

**National Drug Research Institute  
Faculty of Health Sciences**

**Disadvantage and Disease:  
Experience of Type 2 Diabetes among Low Income Earners  
in Perth, Western Australia**

**Maria Beatriz Cuesta Briand**

**This thesis is presented for the Degree of  
Doctor of Philosophy  
of  
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# Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

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## **Abstract**

Diabetes prevalence is increasing in Australia and worldwide. An estimated four per cent of the Australian population in 2007–08 had been diagnosed with diabetes, and figures show stark inequities in prevalence and clinical outcomes among Indigenous people and low socio-economic groups.

This qualitative study explored the impact of socio-economic disadvantage on the experience of type 2 diabetes in Perth, Western Australia. The objectives of the study were to: explore the attitudes and experiences of persons at socio-economic disadvantage living with type 2 diabetes with respect to living with and self-managing their disease, the medical management of their disease, and seeking access to healthcare services; analyse participants' perception of the quality of care received, and how those perceptions are formed; and elicit priorities for the effective management of type 2 diabetes from the perspective of disadvantaged health consumers.

The study was positioned within a social justice and health equity framework, with a strong emphasis on the social determinants of health. The study drew from an existing conceptual framework on the relationship between socio-economic position and health among persons with type 2 diabetes to explore the pathways of disadvantage leading to poorer health outcomes.

Data were collected through focus groups and semi-structured interviews held from October 2008 to November 2009. The sample, comprising 38 participants (Indigenous and non-Indigenous), was recruited from areas with high indices of disadvantage in the Perth metropolitan area. Deductive data analysis identified categories from the conceptual framework for the relationship between socio-economic position and diabetes health outcomes, while an inductive approach was adopted to identify new themes.

The study unveiled multilevel pathways through which socio-economic status influences diabetes health outcomes in a sample of low income earners. A modified framework is presented which highlights the main pathways of disadvantage based on the study results, and emphasizes the complex, interweaving factors shaping the

structural and psychosocial environment in which disadvantaged individuals experience their disease.

Study results suggest that the circumstances in which the experience of disease of disadvantaged populations are embedded need to be understood and addressed in order to reduce the inequities surrounding diabetes outcomes.

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## List of Acronyms and Abbreviations

ABS	Australian Bureau of Statistics
AHP	Allied Health Professional
AHW	Aboriginal Health Worker
AIHW	Australian Institute of Health and Welfare
AusDiab	Australian Diabetes, Obesity and Lifestyle Study
BEACH	Bettering the Evaluation And Care of Health
BMI	Body Mass Index
BSL	Blood Sugar Level
CaLD	Culturally and Linguistically Diverse
CBD	Central Business District
CHD	Coronary Heart Disease
CKD	Chronic Kidney Disease
CSDH	Commission on Social Determinants of Health
CSIRO	Commonwealth Scientific and Research Organisation
CVD	Cardiovascular Disease
DAGDC	Diabetes Australia Guideline Development Consortium
DALY	Disability-Adjusted Life Year
DAWN	Diabetes Attitudes Wishes and Needs
DCRG	Diabetes Consumer Reference Group
DSME	Diabetes Self-Management Education
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
FYRM	Former Yugoslav Republic of Macedonia
GI	Glycaemic Index
GIS	Geographical Information System
GP	General Practitioner
GPMP	General Practice Management Plan
HACC	Home and Community Care
HbA <sub>1c</sub>	Glycated Haemoglobin

HCC	Health Consumers' Council
HDL	High-Density Lipoprotein
HMR	Home Medication Review
IDF	International Diabetes Federation
IFG	Impaired Fasting Glucose
IGT	Impaired Glucose Tolerance
IRSD	Index of Relative Socio-economic Disadvantage
LDL	Low-Density Lipoprotein
MRC	Mirrabooka Regional Centre
NDRI	National Drug Research Institute
NDSS	National Diabetes Services Scheme
NHMRC	National Health and Medical Research Council
NHS	National Health Survey
NSW	New South Wales
OECD	Organisation for Economic Co-operation and Development
OHA	Oral Hypoglycaemic Agent
PYLL	Potential Years of Life Lost
QDAS	Qualitative Data Analysis Software
RPH	Royal Perth Hospital
SCGH	Sir Charles Gairdner Hospital
SCRGSP	Steering Committee for the Review of Government Service Provision
SDH	Social Determinants of Health
SEIFA	Socio-Economic Indexes For Areas
SEP	Socio-Economic Position
SES	Socio-Economic Status
SMBG	Self-Monitoring of Blood Glucose
SSS	Subjective Social Status
TAFE	Technical And Further Education
TCA	Team Care Arrangement
TRIAD	Translating Research Into Action for Diabetes
T2D	Type 2 Diabetes



UK	United Kingdom
UN	United Nations
UNDP	United Nations Development Program
US	United States
WA	Western Australia
WADoH	Western Australia Department of Health
WHO	World Health Organization



# Chapter 1 – Introduction

*Even in the most affluent countries, people who are less well off have substantially shorter life expectancies and more illnesses than the rich.*

(World Health Organization)

## Australia: A healthy nation?

By international standards Australia is, overall, a healthy nation. According to a report published by the United Nations Development Programme (UNDP) in 2010, Australia has one of the highest rankings in the world – second only to Norway – by the Human Development Index, a composite measure of achievement in three dimensions of human development including a long and healthy life, access to knowledge, and a decent standard of living (UNDP 2010). Indeed, Australians enjoy one of the highest life expectancies in the world. In 2007, the life expectancy at birth for the total population (males and females combined) was the fourth highest in the world at 81.4 years – following Japan, Switzerland and Italy; the male life expectancy ranked fourth at 79.0 years; while the life expectancy for Australian females stood sixth at 83.7 years (OECD 2010). Australia also ranks well against countries from the Organisation for Economic Co-operation and Development (OECD) on measures of mortality, risk factors, self-rated health and morbidity (AIHW 2010); however, obesity levels are among the highest in the world (Finucane *et al.* 2011), and the ranking on infant mortality among OECD countries decreased from the middle third to the worst third between 1987 and 2006 (AIHW 2010).

Despite the overall high levels of health and well-being enjoyed by Australians, these are not shared equally across all population groups (Korda *et al.* 2007). The unequal distribution of disease and risk factors in Australia is of concern, and data published by the Australian Institute of Health and Welfare (AIHW) show that several groups experience various levels of health disadvantage: Indigenous<sup>1</sup> people are generally less healthy, die at much younger ages, and have more disability and a lower quality of life than non-Indigenous Australians; people living in rural and remote areas tend to have higher levels of disease risk factors and illness than those in major cities; disadvantaged Australians are more likely to have shorter lives; while people with a

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<sup>1</sup> Indigenous is used to refer to the two Indigenous populations of Australia: Australian Aboriginal peoples and Torres Strait Islanders.

disability and prisoners also experience worse health compared with the general community (AIHW 2010).

Socio-economic factors such as education, occupation and income help explain many of the health inequalities in Australia (AIHW 2010). Although in Australia social security entitlements mean that individuals have theoretical access to the means to avoid absolute poverty (Saggers and Gray 2007), social gradients in health exist, that is, those at the highest end of the socio-economic status (SES) spectrum have better health than those at the lower end (Marmot 2004). In general, relatively disadvantaged members of society have shorter lives, and have higher rates of illness, disability and death than those relatively advantaged (AIHW 2010). In Australia, there is a graded relationship between death rates and SES, and the life expectancy gap between the highest and lowest SES groups is four years for males and two for females (Draper, Turrel, and Oldenburgh 2005). The rate of avoidable mortality in Australia from 1997 to 2001 was 80 per cent higher for the most disadvantaged areas than for the least disadvantaged (Page *et al.* 2006); and a trend analysis over the period 1986 to 2002 shows that although the absolute SES mortality gap has decreased due to access to health care, advantaged people have obtained a disproportionate benefit of health care, contributing to a widening of relative health inequalities (Korda *et al.* 2007). Furthermore, a study examining the distribution of major chronic diseases and their risk factors across socio-economic groups in Australia showed the existence of social gradients for a number of specific conditions such as diabetes and diseases of the circulatory system, as well as for important disease risk factors such as smoking and physical inactivity (Glover, Hetzel, and Tennant 2004).

The health disadvantage affecting some populations in Australia is overshadowed by the stark inequalities affecting Indigenous Australians, who, despite slow improvements, remain the least healthy population group in Australia (Thomson *et al.* 2010). The life expectancy gap between Indigenous and non-Indigenous Australians is 12 years for males and 10 years for females, and mortality rates are almost twice as high for Indigenous people compared with their non-Indigenous counterparts (AIHW 2010); Indigenous people are exposed to higher rates of disability and chronic disease; and infant mortality rates are twice as high for Indigenous than for non-Indigenous people (AIHW 2010). The vast gap between the

health of Indigenous and non-Indigenous Australians was highlighted by the Aboriginal and Torres Strait Islander Social Justice Commissioner in its *Social Justice Report 2005*, which called on Australian governments to commit to achieving Indigenous health equality by 2030 (Aboriginal and Torres Strait Islander Social Justice Commissioner 2005), and sparked the *Close the Gap* campaign launched by health peak bodies and human rights organisations (Calma 2009).

The causes of Indigenous health inequalities are historical and inextricably linked to dispossession and exclusion (Saggers and Gray 2007); however, their perpetuation is linked to contemporary structural and social factors (Thomson *et al.* 2010), and Indigenous Australians' exposure to a 'constellation of disadvantages' (Baum 2004, 247) relating to education, employment status, economic status, housing, and lack of appropriate environmental infrastructure. Consistent with this appreciation of the social determinants of Indigenous health, the Council of Australian Governments agreed on key targets for reducing Indigenous disadvantage in areas of health, early childhood development, education and employment; the health key targets are to close the life expectancy gap within a generation, and halve the gap in mortality rates for Indigenous children under five within a decade (FaHCSIA 2009).

## **Health inequalities and the 'duty to be healthy'**

There is now overwhelming evidence around the social determinants of health, and an understanding that inequalities in the social and structural circumstances in which people live are responsible for most of the health inequalities observed between and within countries (CSDH 2008). However, the notion that socio-structural conditions have an impact on health is sometimes difficult to assert in an era characterised by an increasing emphasis on personal responsibility (Saggers and Gray 2007).

Personal responsibility is a key tenet of the discourse of 'healthism', a preoccupation with health first described in the 1980s (Crawford 1980) and whose 21<sup>st</sup> century reinterpretation has become one of the guiding mantras of both governments and individuals (Cheek 2008). This health consciousness movement has been reinforced in the social and bio-medical rhetoric: in the media, the health discourse is converging with discourses of anti-ageing, anti-death, and anti-disease which have become normalised (Cheek 2008); while at the public policy level, the practical

consequence of the risk factor approach has been to stress the modifiable risks which health education can hope to address, transforming a concern for health into an individual responsibility (Blaxter 1997).

Recommendations for a healthier life have been around for a few decades, but, increasingly, these recommendations have been transformed into expectations about individual responsibility for one's health (Michailakis and Schirmer 2010). In Western societies, being healthy has become a moral imperative, a 'moral code' against which individuals are judged (Litva and Eyles 1994, 1089); the right to be healthy has, thus, become the duty to be healthy (Blaxter 1997). In this context, being ill – failing to be healthy – is increasingly seen as a moral failure (Galvin 2002); Susan Sontag's notion of illness as a metaphor implying adverse moral and psychological judgements about the ill person (1978) has become consolidated.

The notion of personal responsibility promotes an assumption of individual blame (Crawford 1980), which has been brought to the fore in the obesity debate (Magnusson 2009), and has led some authors to denounce the 'moral panic' around the epidemiology of overweight and obesity, which blames and stigmatises, claiming that talk of an 'obesity epidemic' is serving to reinforce moral boundaries against disadvantaged populations (Campos *et al.* 2006).

Thus, being healthy helps define an individual's place in the world (Litva and Eyles 1994) and its moral imperatives have implications for how lay people perceive the causes of health inequalities. It is the more advantaged who are more likely to be aware of structural factors contributing to health inequalities (Blaxter 1997), while disadvantaged people are reluctant to accept the existence of health inequalities (Popay *et al.* 2003), since to acknowledge inequality would be to admit an 'inferior moral status' (Blaxter 1997, 754).

The increasing emphasis on personal responsibility is happening at a crossroads of contemporary influences such as neo-liberal thought, market-based notions of health and health care, and an emphasis on individualism and individual autonomy (Cheek 2008). The concept of universal needs in health and welfare is losing its relevance, with the growth in self-help and consumer movements placing more emphasis on personal choice and individual determination of need (Bunton 1998). However, it has been noted that 'the principle of autonomy, interpreted as non-interference with the

individual's free choice (and its correlate 'individual responsibility') is a moral standpoint usually adopted from an advantaged social position' (Lindbladh *et al.* 1998, 1018), and emphasis on autonomy will tend to result in public health strategies which are consonant with the views of those in the highest social classes (Lindbladh *et al.* 1998).

The over-emphasis on personal responsibility has been translated to the chronic disease arena, and it is of particular salience because individuals affected by chronic disease are often required to engage in a number of self-management behaviours; chronic disease can, thus, be seen as a specific instance of personal moral failure (Galvin 2002). As the pressure on healthcare systems increases, it is argued that the emphasis of self-management of chronic disease is consistent with a wider, neo-liberal climate in which governments seek to have individuals accept a greater responsibility for their health (Jamrozik 2010). This shift from collective towards individual responsibility is also occurring in welfare states such as Sweden, where a proposal for a 'responsibility principle' has been put forward that would down-prioritise those who neglect their health or choose risky lifestyles (Michailakis and Schirmer 2010).

Crawford noted that the language of self-care and individual responsibility obscures the power relations underlying the social production of disease (1980). Given the increased emphasis on individual responsibility which has characterised the current public health discourse both in Australia (Jamrozik 2010) and overseas (Roy 2008; Michailakis and Schirmer 2010), and the increasing inequities in the distribution of health and illness, it seems especially relevant to explore the socio-structural circumstances in which disadvantaged people experience chronic disease to better understand how these circumstances may place limits on their ability to make 'lifestyle choices' and, thus, comply with the 'duty to be healthy'.

## **My personal motivation**

This study is largely the result of my health advocacy work, and my personal interest in social justice and health inequalities, and in the ideology driving health promotion discourses, and public health more broadly. It is also partly the result of my personal journey through the complexities of the Australian healthcare system – a mix of

public and private services which I experienced first-hand shortly after my arrival in Australia in 2002.

My advocacy work in the aged care sector first exposed me to the health and social issues faced by vulnerable, resource-poor populations in Australia; while through my involvement in the cancer sector – working closely with cancer survivors and their carers – I became aware of the inequalities surrounding access to cancer services and clinical outcomes, and the psychosocial impact of cancer on patients and their families. This work sparked in me an interest in health inequalities which, coupled with a strong sense of social justice, led me to explore the links between disadvantage and chronic disease, and turn my attention to type 2 diabetes (T2D) – the disease showing the strongest social gradient in Australia (Glover, Hetzel, and Tennant 2004).

## **Significance of the study**

Diabetes is a significant health problem in Australia, with increasing health, financial and societal burdens (AIHW 2008b). In addition to the health burden associated with the disease and its complications, the financial burden of T2D has been estimated at \$6 billion<sup>2</sup> per year, including direct costs to the healthcare system, community resources used by people with diabetes, out-of-pocket expenses borne by people with diabetes and their carers, and impact on quality of life (Colagiuri *et al.* 2003). Furthermore, the socio-economic inequalities embedded in the distribution of its prevalence add to the societal burden of diabetes, and contribute to the unjust widening of the health gaps between Australian population groups.

This study is a significant contribution to the body of research as it adds to the limited body of qualitative data on the lay experience of T2D in Australia. To my knowledge, this is the first study which explores the experience of T2D across the spectrum of socio-economic disadvantage, including Indigenous and non-Indigenous participants. This study contributes to the body of research by providing an understanding of how socio-economic disadvantage impacts on T2D, unravelling specific pathways of disadvantage within a social determinants of health framework. Furthermore, this study identifies potential barriers to effective disease management

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<sup>2</sup> All figures are in Australian dollars unless otherwise stated.



in a disadvantaged, urban setting; and identifies priorities for more effective management strategies among disadvantaged populations.

## **Aim and objectives of the study**

This qualitative study was firmly grounded within a social determinants of health framework. Its overall aim was to explore how persons at a socio-economic disadvantage living with T2D experience their disease, and how socio-economic disadvantage impacts on their disease management. The specific objectives were to:

- 1) Explore the attitudes and experiences of persons at a socio-economic disadvantage living with T2D with respect to:
  - a. Living with and self-managing their disease;
  - b. The medical management of their disease; and
  - c. Seeking access to healthcare services for the management of their disease.
- 2) Analyse the perceptions of disadvantaged persons living with T2D of the quality of care received, and how these perceptions are formed; and
- 3) Elicit the priorities for the effective management of T2D from the perspective of the disadvantaged health consumers.

## **Thesis overview**

This thesis is divided into 12 chapters. In Chapter 1, I provide an introduction to the research topic, positioning it in the Australian context; and discuss the significance of the study, and its aim and objectives. A review of the relevant literature is presented in Chapter 2, including an overview of the literature on social justice and health equity, the social determinants of health, and the link between chronic disease and disadvantage, with a particular consideration of the literature on the link between diabetes and disadvantage. In Chapter 3, I discuss the multi-level conceptual frameworks underpinning the study, with an emphasis on a framework on the relationship between socio-economic position and diabetes health outcomes; while in Chapter 4, I discuss the qualitative methodology adopted in the study.

Two chapters follow that set the background against which participants' experience of disease can be better understood: in Chapter 5, I provide a broad description of the suburbs from which the sample was drawn, including a description of the physical and social environment, and the socio-economic characteristics of the people living

in the area; while in Chapter 6, I discuss the model of care for the management of T2D in Australia.

The results of the study are aligned with the objectives of the study, and I present them in four separate chapters: participants' experience of self-management in Chapter 7; participants' broad experience of disease in Chapter 8; the results relating to participants' experience of medical management, including their perceptions of the quality of their care, in Chapter 9; and, finally, participants' priorities for a more effective management of diabetes in Chapter 10.

In Chapter 11, I discuss the main findings of the study, and present a proposed modified framework highlighting the main pathways of diabetes disadvantage based on the study results. This discussion chapter is followed by a brief conclusion presented in Chapter 12, which includes recommendations for further research, and implications for policy and practice.

## Chapter 2 – Literature Review

*The development of a society, rich or poor, can be judged by the quality of its population's health, how fairly health is distributed across the social spectrum, and the degree of protection provided from disadvantage as a result of ill-health.*

(Commission on Social Determinants of Health)

### **Social justice and health equity**

In this section, I begin by reviewing the literature on social justice as it relates to health, exploring the origins of the notion of 'social justice', its application to health issues, and its association with the notions of human rights and health equity. This is followed by a broad review of the literature on health equity, where I discuss the different approaches to measuring health inequalities and the justification for the study of the social determinants of health as the basis for tackling health inequities.

### ***Social justice and health***

The notion of 'social justice' and its application to health have been the object of philosophical and political debate since John Rawls published his *Theory of Justice* in 1971. In this seminal work, Rawls discussed the notions of justice and fair distribution of social and economic advantages, introducing his theory of 'Justice as Fairness'. Rawls articulated his theory of justice around two principles: each person is to have the most extensive basic liberties compatible with similar liberties for others; and social and economic inequalities are to be arranged so that they are of benefit to all under conditions of fair equality of opportunity (Rawls 1971).

Rawls distinguished between 'social primary goods' – such as income and wealth – and 'natural primary goods', and limited his justice theory to the former, arguing that natural goods cannot be the object of distributive justice. Health was considered a 'natural good', and the assumption was that society could not influence its distribution (Vågerö 1995). In *Just Health Care*, published in 1985, Norman Daniels extended the application of Rawls' theory of justice to health, arguing that health is a 'special' good which is particularly desirable, and that the principle of fair equality of opportunity may be restricted if an individual's health is impaired (Daniels 1985).

Thus, as a special good, health has a value *per se* as well as an instrumental value, influencing an individual's life chances; and both these dimensions carry moral importance (Vågerö 1995). The notion that health is a special good was highlighted by Anand at the first meeting of the International Society for Equity in Health (2010) held in 2000, arguing that health has an intrinsic and an instrumental value, and it is a prerequisite for a person's well-being (2002). Further, Anand declared that poor health reduces the full scope of human agency, and stated that 'inequalities in health constitute inequalities in people's capacity to function' (2002, 486) and, thus, contravene Rawls' principle of 'fair equality of opportunity'.

Although social justice is best understood as part of the broader concept of 'justice', and concerns the distribution of benefits and burdens among the members of society (Miller 1976), it is also concerned with the protection of the rights of individuals, particularly of those who are disadvantaged in society (Baum 2004). Social justice is also closely associated with the notions of human rights and equity, and the *Universal Declaration of Human Rights* proclaimed by the United Nations (UN) General Assembly in 1948 (Office of the High Commissioner for Human Rights 2011) established a benchmark against which to assess equity in health (Bambas and Casas 2003). Its Article 25 declares that everyone has the right to a standard of living adequate for his or her health and well-being, including food, clothing, housing and medical care; while Article 2 enshrines the principle of non-discrimination, stating:

Everyone is entitled to all rights and freedoms set forth in this Declaration without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status (United Nations General Assembly 1948, 72).

Braveman and Gruskin argue that 'the notion of equal opportunities to be healthy is grounded in the human rights concept of non-discrimination' (2003, 255), thus making it the responsibility of governments to implement the necessary strategies to eliminate reverse discrimination. In her review of the concepts and measurements of health disparities and health equity, Braveman argues for the existence of the right to health itself, which the author includes among the economic, social and cultural rights (2006). This 'right to health' is conceptualised as the right to the highest

attainable standard of health, that is, that ‘enjoyed by the most socially advantaged group within a society’ (Braveman and Gruskin 2003, 255).

Thus, ideas of social justice have an impact on how disease prevention is understood and how public health is viewed. Beauchamp states that rather than conceiving public health narrowly as an instrumental activity, it should be a ‘way of doing justice’ (Beauchamp 2003, 276), and argues that the model of public health as social justice is a reaction to ‘market-justice’, a model of justice dominant in many developed countries – particularly in the United States (US) – with its emphasis on individualism, minimal collective action, and freedom from collective obligations except to respect other individuals’ fundamental rights.

A major aim of public health is reducing inequities in health status (Baum 2004); however, it is argued that a trend towards individualisation has led to the principle of autonomy, interpreted as individual, free choice, coming into conflict with the principle of health equity (Lindbladh *et al.* 1998). Furthermore, it is argued that health inequities could be addressed in the name of national efficiency rather than in pursuit of social justice (Vågerö 1995); thus, there is a tension between the utilitarian argument and the social justice argument in the justification of addressing health inequities. Amartya Sen’s capability approach provides an alternative philosophical framework to address the issues of justice and health (Prah Ruger 2004). Sen’s approach was developed in the 1980s and is based on the notion of capacity to function, or what a person can do or can be (Sen 1987). This approach is more ‘people-centered’ and ‘agency-centered’, and in so far as it sees the expansion of human capabilities and freedoms as the ultimate end of public policy (Prah Ruger 2004), it could be seen as supporting the utilitarian argument.

This study is underpinned by a social justice approach, and I concur with the view that, without a perspective grounded in values of social justice, approaches to inequities in health will likely aim at symptoms, continuing to rely on individual interventions rather than addressing the social and structural drivers which cause health inequities (Hofrichter 2003). This approach is consistent with that adopted by the Commission on Social Determinants of Health (CSDH) when it declares in the preamble to its final report to the World Health Organization (WHO) that:

Social justice is a matter of life and death. It affects the way people live, their consequent chance of illness, and their risk of premature death (CSDH 2008).

## ***Health equity***

Health and illness are not evenly distributed among populations. Despite dramatic improvements in health globally, gross inequities remain between and within countries (CSDH 2008). It is argued that health inequalities are one of the greatest challenges to public health (Kawachi, Subramanian, and Almeida-Filho 2002), and although equity has been the explicitly stated or implied goal of health policy in many countries and international organisations for decades (Östlin *et al.* 2005), some issues in this field of research remain controversial.

Since 1991, when Margaret Whitehead defined health inequities as those differences in health which ‘are unnecessary and avoidable but, in addition, are also considered unfair and unjust’ (1991, 219), terms such as ‘health equity’, ‘health inequalities’ or ‘health disparities’ have been used inconsistently, and there is little consensus about their meaning (Braveman 2006). Some authors refer to ‘health inequalities’ when discussing health inequity issues (Prah Ruger 2004); while the literature emerging from the US tends to refer to ‘health disparities’ rather than ‘health inequalities’ (Braveman 2006).

When reviewing the existing literature on health equity from 1980 to 2001, Mackinko and Starfield found that common to most definitions is the idea that some health differences are unfair or unjust; it is that subset of health inequalities that constitute health inequities (2002). Health equity, thus, would be the absence of unjust health inequalities. Health equality is based on the notion of ‘sameness’, whereas health equity is based on ‘fairness’ (Bambas and Casas 2003). Thus ‘health inequality’ is a generic term which designates differences or variations between the health status of groups or individuals; while ‘health inequity’ refers to those inequalities which are deemed to be unfair or stem from some sort of injustice (Kawachi, Subramanian, and Almeida-Filho 2002).

Braveman and Gruskin critiqued Whitehead’s definition of health inequity, recommending that ‘avoidability’ not be used as a criterion to define equity in health.

They argue that this criterion is unnecessary, because ‘avoidable’ is implied in ‘unfair’ and ‘unjust’, and also because it would be undesirable to use ease of avoidability as a measure of the degree of inequality (2003). The academic debate surrounding the notion of health inequity is highlighted by the complexity of Braveman’s own proposed definition:

A ‘health disparity/inequality’ is a particular type of potentially avoidable difference in health or in important influences on health that can be shaped by policies; it is a difference in which a disadvantaged social group or groups (such as the poor, racial/ethnic minorities, women, or other groups who have persistently experienced social disadvantage or discrimination in the past) systematically experience worse health or greater health risks than the most advantaged social groups (Braveman 2006, 180).

Following Whitehead’s original definition (Whitehead 1991), and Kawachi, Subramanian and Almeida-Filho’s interpretation (2002), in this thesis ‘health inequality’ will be used as a generic term alluding to variations between health status or outcomes, while ‘health inequity’ will be used to refer to those differences which are unfair and unjust.

The majority of the published literature on health equity has focused on equity in health care, that is, access, utilization and financing of health services (Macinko and Starfield 2002). However, Braveman and Gruskin call for addressing the social and economic determinants of health, including not only health care, but also living conditions, working conditions, and policies that affect any of these factors, stating that equity in health means the absence of social disparities not only in health status but also in its key social determinants (Braveman and Gruskin 2003). This social determinants approach is that adopted in this study.

## **The social determinants of health**

In this section, I present a broad overview of the wealth of published literature on the social determinants of health (SDH). I begin by discussing the origins and evolution of the notion of the SDH; I then present a broad review of the literature reporting on the evidence on the links between social conditions and health, with an emphasis on the evidence from high-income countries; and I conclude by discussing the policy implications of adopting a SDH framework to address public health issues.

## ***The social determinants of health: Origins and current understandings***

The social determinants of health are the conditions of daily life – the circumstances in which people are born, grow, live, work, and age – and the structural drivers of those conditions (CSDH 2008). These non-medical determinants of health (Braveman 2006) or ‘health determinants outside the healthcare system’ (Prah Ruger 2004, 1092) are responsible for a major part of health inequities between and within countries (CSDH 2008).

Recognition of the links between social conditions and health date back to medieval times in Europe and, more recently, to the development of ‘social medicine’ (Lynch 2000). The understanding of the role of social factors in the development of disease embodied in ‘social medicine’ coincided in time with the origins of the ‘biomedical model’ of health, based on the notion of health as the ‘absence of disease’. The limitations of the ‘biomedical model’, particularly its reductionism – the way in which the model objectifies the body at the expense of the whole person – led to the resurgence of interest in social models of health in the first half of the 20<sup>th</sup> century (Saggers and Gray 2007).

*The Black Report*, commissioned in 1977 to examine the patterns of health inequalities in the United Kingdom (UK), showed clear differences between the health profiles of different occupational ‘classes’ or groups, with those in the lowest occupational levels experiencing higher chronic disease and mortality rates than those in the highest levels (Black *et al.* 1982). The publication of this seminal report, sparked more research both in Europe and Australia (Loxley *et al.* 2004), and led to the development of social epidemiology, the branch of epidemiology which studies the social distribution and social determinants of states of health (Berkman and Kawachi 2000). Also in the UK, *The Acheson Report*, published in 1998, highlighted three main areas which needed to be addressed in order to tackle health inequalities: improving the health of families with children; evaluating all policies in terms of their impact on health inequalities; and reducing income inequalities while improving the living standards of poor households (1998). This influential report was followed by *The Solid Facts*, an overview of the evidence on the SDH published by WHO which highlighted nine specific factors which have been associated with better



or worse health outcomes: stress; early development and education; social exclusion; work; unemployment; social support; addiction; food; and transport (WHO 2003).

The notion of the SDH has been the object of on-going debate between those supporting a neo-materialist view, and those favouring a psychosocial interpretation. *The Black Report* adopted a ‘materialist’ or ‘structural’ view on the explanation of health inequalities, stressing the importance of material conditions of life (Black *et al.* 1982). More recently, Lynch and colleagues support a neo-materialist interpretation of the SDH, arguing that health inequalities result from the differential accumulation of exposures that have their sources in the material world – income inequality being one of those material conditions (2000). Marmot and Wilkinson, on the other hand, place more importance on the psychosocial effects of relative deprivation such as insecurity, anxiety or social isolation, and argue that material conditions do not adequately explain health inequalities in developed countries (2001). Thus, health inequalities derive from the direct or indirect effects of stress stemming from living under conditions of relative socio-economic disadvantage (Kawachi, Subramanian, and Almeida-Filho 2002). This psychosocial interpretation is supported by a recent study which explored the potential role of subjective social status (SSS) – the individual’s perception of their own position in the social hierarchy (Jackman and Jackman 1973) – as a mediator for the associations between indicators of SES and health, and found that SSS was significantly related to self-rated health, depression, and long-standing illness or disability, in both men and women (Demakakos *et al.* 2008). This study supports a neo-materialist interpretation of the SDH (see Chapter 3); however, I concur with the view that materialist and psychosocial perspectives are not mutually exclusive; rather, the debate is about relative importance (Eckersley 2004).

A new understanding of how the SDH operate is the ‘life-cycle’ or ‘life-course’ approach, as a growing body of research shows that developmental pathways and life transitions are crucial to health later in life (Eckersley 2004). Longitudinal studies have demonstrated that inequalities in health accumulate over the life cycle (Lynch, Kaplan, and Salonen 1997; van Kippersluis *et al.* 2010), and have brought about a shift in research emphasis from the description of circumstances at a specific point in time, to the focus on change, time and causality (Rees Jones 2003). In their review of studies examining the association between indicators of SEP during early life with

health over the lifespan, Chittleborough and colleagues identified three life-course models: the critical period model implies that there is period in early life during which exposures to deprivation have long-term effects on adult health, regardless of adult circumstances; the pathway model views early exposures as important, but only because they influence the person's socio-economic trajectories; and the cumulative model, which is based on a dose-response effect of physical and social environments throughout life on health (2006). This life-course perspective on the SDH is the approach adopted by the CSDH in their final report to WHO; furthermore, the Commission appears to support a cumulative model approach when it states that:

Implicit in the work of the Commission is a lifecourse perspective on how the social determinants of health operate at every level of development – pregnancy and childbirth, early childhood, childhood, adolescence, and adulthood – both as an immediate influence on health and to provide the basis for health or illness later in life (CSDH 2008, 49).

### ***The evidence on the link between social conditions and health***

A large body of research exists in the area of the SDH, and there is now overwhelming evidence that health inequalities are the product of social and environmental factors (WHO 2003; CSDH 2008; Lynch *et al.* 2003). Much of the research effort has focused on income and the health effects of income inequalities, and although the evidence of the association between countries is mixed, income inequality and health have been linked within the US, the UK and Brazil (Lynch *et al.* 2003). Research has also focused on the association between SES – typically including measures of income, education and occupation – and health, and research has shown a link between SES and mortality (Korda *et al.* 2007; Tobias and Yeh 2007), and between SES and morbidity, in particular chronic diseases such as diabetes and heart disease (Banks *et al.* 2006). Furthermore, there is evidence of a widening gap in socio-economic inequalities in mortality in high-income countries such as Denmark, Finland, Norway, Sweden, England and Wales, Italy (Mackenbach *et al.* 2003), and Australia (Korda *et al.* 2007). It has to be noted that the US is one of the few high-income countries which do not routinely report health statistics by SES, reporting instead by 'race'. Kawachi and colleagues argue that 'race' and SES – which the authors refer to as 'class' – are separate constructs and 'race' cannot be

used as a proxy for SES, proposing that health equity impact assessments in the US should examine both (2005).

Although the focus has been on socio-economic inequality, Eckersley points out that there are other ways to ‘slice the ‘health inequalities’ cake’ (2004, 69) by examining the inequality between genders, race and ethnicity, marriage, social isolation, and even religious affiliation. Other authors claim that there is a need to position research on the SDH within a broader socio-political framework that looks beyond SES differences, and examines: the importance of political systems in shaping social inequalities and population health (Navarro and Shi 2001); the role of neo-liberal politics and policies, and their negative impact on health equity (Coburn 2004); or the impact of the current direction of globalization policy – with its emphasis on austerity, privatisation, and deregulation – on health inequalities (Pappas, Hyder, and Akhter 2003). Thus, health care in its broad sense – comprising the receipt of healthcare services, but also other aspects such as the allocation of resources, financing, and the quality of healthcare services – can also be considered a social determinant of health, in so far as it is influenced by social policies (Braveman and Gruskin 2003).

As part of this broad understanding of the SDH, a new appreciation of the importance of ‘place’ has emerged, leading to the conceptualisation of neighbourhoods as providers of resources influencing the production of health inequalities (Bernard *et al.* 2007). At an individual level, places may influence health and illness through direct exposure or by influencing health-related behaviours; and at a population level, places influence social processes, which in turn may influence health (Burgess and Morrison 2007). There is an increasing interest in exploring the link between the built and social environment, and health and health behaviours; and this field of research has been aided by the use of new technologies, such as the incorporation of a Geographical Information System (GIS) approach to measure community resources accessibility (Pearce, Witten, and Bartie 2006). Research conducted in the US (Morland and Filomena 2008), the UK (Guy and David 2004) and Australia (Harrison *et al.* 2010) has unveiled socio-economic disparities in access to healthy and affordable food; while a review of the literature showed that environmental factors including residential density and physical infrastructure are consistently associated with levels of physical activity (Gebel, Bauman, and

Petticrew 2007). Thus, there is a growing recognition that the contemporary built environment has an impact on diet and physical activity, and may adversely affect our health (Townshend and Lake 2009).

There is also an increasing understanding of the social environment as a health determinant. McNeill, Kreuter and Subramanian identified several social environmental dimensions which influence behaviour: social support and social networks; SEP and income inequality; racial discrimination; neighbourhood factors; and social cohesion and social capital (2006). Social networks influence health through providing social support, but also through other behavioural mechanisms including forces of social influence, levels of social engagement and participation, and access to material goods and resources (Berkman and Glass 2000). Social capital can be defined as the level of trust and level of involvement in community life (Wilkinson 2005); it is a contextual phenomenon, alluding to the characteristics of relationships and interactions between individuals, groups, organisations and institutions (Lindström 2008). Social capital is an important asset that makes a substantial contribution to quality of life (Wilkinson 2005), and research conducted in Australia using scales of reciprocity, trust, friendliness, civic engagement, community concern, support and networks has shown that social capital increases with income (Wood *et al.* 2008).

This study primarily focuses on the relationship between individual-level SES and health; however, the role of social networks is examined (see Chapter 3), and the physical and socio-demographic characteristics of the place and its people are also considered (see Chapter 5).

### ***Implications of adopting a SDH framework***

The adoption of a SDH framework has implications for both epidemiological research and public health strategies on disease prevention. The renewed appreciation of the importance of social conditions in health has led to the development of multilevel models for assigning causality in public health that take into account not only genetic and individual characteristics, but also social connections and structural macrosocial factors (Lynch 2000). This understanding has led, in turn, to the development of disease-specific conceptual frameworks for the relationship between SEP and health, such as the one proposed by Brown and

colleagues (2004), which highlights the proximal and distal factors that influence health outcomes for people living with diabetes, and identifies causal pathways leading to poor health outcomes. This framework is one of the main theoretical underpinnings of the study and is discussed in detail in Chapter 3.

Regarding health and illness as being influenced by socio-structural determinants also has an impact on the way in which public health policy and strategies are viewed. It is now understood that individual behaviours are not randomly distributed in a population; rather, the social environment influences behaviour by shaping norms, enforcing patterns of social control, providing (or not) environmental opportunities to engage in certain behaviours, and reducing or producing stress (Berkman and Kawachi 2000). Thus, any population strategy of prevention has to operate on a wider base, addressing the underlying causes of disease, or the ‘causes of the causes’ (Rose 1992, 99). Furthermore, the social determinants of poor health can only be addressed by societal solutions which require greater collaboration between public health researchers, policy makers and communities (Heymann 2000).

The broad implications of addressing health inequalities within a SDH framework are brought to the fore by the breadth of recommendations presented by the CSDH in its final report to WHO. Formed in 2005 in recognition of the urgency of addressing the SDH and chaired by Michael Marmot, the CSDH calls for ‘closing the health gap in a generation’ (2008, 1), and sets out a number of broad areas of action under three overarching recommendations, covering a wide range of social and economic policies, and political and governance issues (2008) (see Table 2.1).

Table 2.1: CSDH final report: Recommendations and areas of action.

<b>Overarching Recommendation</b>	<b>Broad Area of Action</b>
Improve daily living conditions	Equity from the start Healthy places – Healthy people Fair employment and decent work Social protection across the lifecourse Universal health care
Tackle the inequitable distribution of power, money, and resources	Health equity in all policies, systems, and programs Fair financing Market responsibility Gender equity Political empowerment – Inclusion and voice Good global governance
Measure and understand the problem and assess the impact of action	Monitoring, training, and research

Source: CSDH (2008).

A SDH approach is of special salience in the consideration of the policy implications of addressing the increasing prevalence of chronic disease, as poverty and social exclusion increase the risk of developing a chronic disease, developing complications, and dying from it; and lead to a widening of the health inequities within countries (WHO 2005a). This approach is the main theoretical underpinning of this study, and is discussed in Chapter 3.

## **Chronic disease and disadvantage**

In this section, I present a broad review of the literature on chronic disease, with an emphasis of the link between chronic disease and disadvantage in high-income countries. An overview of the chronic disease epidemic is presented first, and is followed by a review of the literature on the link between chronic disease and socio-economic disadvantage, with a special consideration of the social gradient for chronic disease and risk factors in Australia.

### ***The increasing burden of chronic disease***

Chronic diseases are the major cause of death and disability worldwide, and their prevalence is on the increase in all regions in the world, prompting some to describe them as an epidemic (Horton 2005; Zimmet 2000; Strong *et al.* 2006). Chronic diseases can be defined as conditions that generally involve a slow progression in their development or a long duration of their symptoms (WHO 2008; AIHW 2005a);

they can affect the person's ability to function normally and, following diagnosis, require adherence to a disease management regimen (de Ridder *et al.* 2008). Chronic diseases are sometimes referred to as 'lifestyle-related' diseases, emphasizing the contribution of individual behaviour to their development, yet these diseases are greatly influenced by environmental and structural conditions, and are not the result of individual choices alone. Chronic diseases are also referred to as 'non-communicable' diseases, to make the distinction from infectious or 'communicable' diseases; however, several chronic diseases such as some types of cancer have an infectious component to their development (WHO 2005a).

According to WHO, the main chronic diseases are: cardiovascular diseases (CVD) – mainly coronary heart disease (CHD) and stroke; cancer; chronic respiratory diseases, such as chronic obstructive pulmonary disease and asthma; and diabetes (2005a). Other chronic conditions and diseases include mental disorders, vision and hearing impairment, oral diseases, bone and joint disorders, and genetic disorders (WHO 2005a); and, in the substance abuse field, addiction is also increasingly being viewed as a chronic condition (McLellan 2002).

Chronic diseases are not new to public health; indeed, diabetes and arthritis, for example, have been known for centuries (AIHW 2005a). However there has been a marked increase in the prevalence of chronic diseases and their risk factors, a fact that needs to be understood in the context of what is known as the 'epidemiological transition' (Zimmet 2000; Omran 1971) or 'health transition' (Davis, Wagner, and Groves 1999). The notion of 'epidemiological transition' was first conceptualised by Omran in the 1970s, and refers to a stage where pandemics of infectious disease are gradually displaced by 'degenerative and man-made diseases' as the main cause of morbidity and mortality (1971, 738). Today, in all high- and middle-income countries, non-infectious diseases have overtaken infectious disease as the main cause of mortality, and among the developing countries, all but the poorest countries are in the process of completing the epidemiological transition (Beaglehole and Yach 2003).

The aetiology of chronic disease is multi-factorial and results from complex interactions between individuals and the environment in which they live (WHO Europe 2006); however, the main chronic diseases share a set of common risk factors

that include modifiable and non-modifiable factors (WHO 2005a). Figure 2.1 shows the list of modifiable and non-modifiable risk factors identified by WHO, as well as the intermediate risk factors through which the mediate risk factors are expressed. The figure also highlights the structural determinants underlying the development of chronic disease, which include poverty, and the global trends of globalisation, urbanisation and population ageing (WHO 2005a). These underlying determinants influence opportunities for health, and health-seeking and lifestyle behaviours (WHO Europe 2006), thus impacting on individual and community disease patterns (Zimmet 2000).

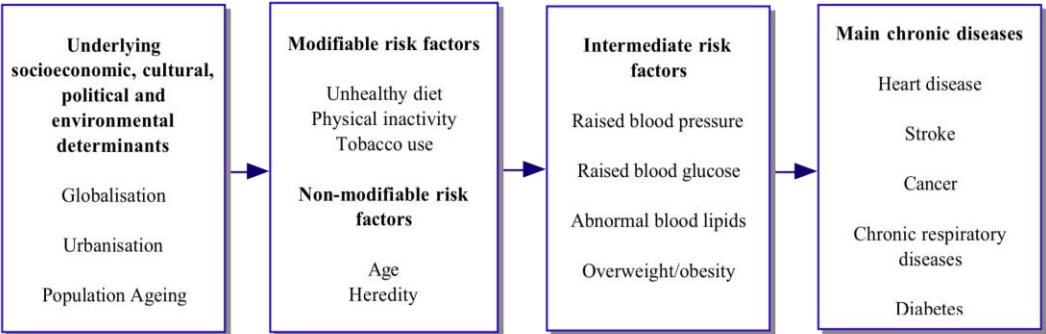


Figure 2.1: Causes of chronic diseases. Source: WHO (2005a).

In recognition of the growing burden of chronic diseases, WHO developed a *Global Strategy on Diet, Physical Activity and Health* to address two of the main modifiable risk factors of chronic disease. The strategy encourages a sustainable, comprehensive and multi-sectoral approach to developing policies and action plans on healthy diet and physical activity, and calls for the involvement of governments, civil society, the private sector and the media (WHO 2004). The recommendations for a healthy diet include: achieving a healthy weight; limiting the total fat intake, and shifting from saturated to unsaturated fats – aiming towards the elimination of trans fatty acids; increasing the consumption of fruits and vegetables; limiting the intake of free sugars; and limiting salt consumption (WHO 2004). Although physical activity is a key determinant of energy expenditure, and thus, is fundamental to weight control, the beneficial effects of physical activity extend beyond controlling excess weight. Physical activity reduces blood pressure, improves abnormal lipid levels, improves control of blood glucose in overweight people, and reduces the risk of colon cancer and breast cancer among women (WHO 2004). It is recommended that individuals engage in adequate levels of physical activity throughout their lives; and 30 minutes



of regular, moderate-intensity physical activity on most days reduces the risk of CVD and diabetes, colon cancer and breast cancer (WHO 2004).

An unhealthy diet coupled with higher levels of physical inactivity linked to urbanisation have led to overweight and obesity<sup>3</sup> rapidly becoming a major public health concern in OECD countries (OECD 2009); and US research forecast that the rise in obesity and its life-shortening complications such as diabetes has the potential to result in an overall decline of life expectancy in the US during the first half of the century (Olshansky, Passaro, and Hershov 2005). A study recently published found that the worldwide prevalence of obesity nearly doubled between 1980 and 2008, and estimated that in 2008 1.46 billion adults worldwide were overweight or obese. Among high-income countries, the US had the highest Body Mass Index (BMI), while Japan had the lowest; and between 1980 and 2008 BMI rose most in the US, while Australia experienced the third largest rise (Finucane *et al.* 2011).

With regard to smoking as a risk factor for chronic disease, there has been a marked decline over recent decades among OECD countries; however, large disparities remain both between and within countries. The adult population smoking daily in 2007 in OECD countries averaged 23.6 per cent, with the lowest proportion in Sweden (14.5 %), and the highest in Greece (40.0 %), while Australia recorded a comparatively low 16.6 per cent (OECD 2009).

Chronic diseases have a significant burden on society worldwide. It is estimated that chronic diseases accounted for 35 million of an estimated total of 58 million deaths in 2005 (WHO 2005a). Among OECD members, CVD is the main cause of mortality, accounting for 36 per cent of all deaths in 2006, while cancer accounts for 27 per cent (OECD 2009). Chronic diseases also cause disability, often for prolonged periods of a person's life, and it is estimated that in 2005, half of the global burden of disease – calculated in Disability-Adjusted Life Years (DALYs) – was caused by chronic diseases (WHO 2005a). In addition, chronic diseases also present a challenge to health systems, absorbing substantial amounts of resources (WHO Europe 2006). The financial burden of chronic disease extends beyond the cost of healthcare services, and includes indirect costs such as lost productivity, the cost of care falling

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<sup>3</sup> Overweight: BMI between 25 and 30. Obesity: BMI over 30.

on patients and their families, plus foregone national income due to premature deaths of main wage-earners (WHO Europe 2006).

In Australia, chronic diseases are responsible for most of the burden of disease, and their prevalence is rising (National Health Priority Action Council 2006). Cardiovascular diseases, cancers and respiratory diseases are the leading causes of death in Australia (AIHW 2010): CHD is the greatest contributor to premature mortality among males, accounting for 10 per cent of all Potential Years of Life Lost (PYLL), while breast cancer is the leading cause of PYLL among females, accounting for 8.7 per cent of the total. In terms of burden of disease, cancer and CVD combined account for 35 per cent of the total DALYs (AIHW 2010). Finally, with regard to the financial burden, CVD is the disease group that accounts for the greatest amount of expenditure, with \$5,942 million or 11.3 per cent of the total health expenditure in 2004–05 (AIHW 2010).

In recognition of their significant contribution to the burden of disease, and their potential for health gains, a number of chronic diseases – arthritis and musculoskeletal conditions, asthma, cancer, cardiovascular disease, and diabetes – have been identified as National Health Priority Areas (AIHW 2005b). In addition, a *National Chronic Disease Strategy* has been developed to provide national policy directions for improving chronic disease prevention and care in Australia, with the aim of improving health outcomes and reducing the impact of chronic disease on individuals, families, communities and society (National Health Priority Action Council 2006).

### ***Chronic diseases and poverty***

A widespread misconception exists that chronic diseases are ‘diseases of affluence’ or ‘diseases of the rich’ because originally chronic diseases were more present in wealthy countries and were associated with economic development (Boutayeb 2006). However, poverty and chronic disease are ‘interconnected in a vicious cycle’ (WHO 2005a, 61). Disadvantaged people are more vulnerable to chronic conditions because of material deprivation, psychosocial stress, higher levels of risk behaviour, and limited access to good-quality health care (WHO 2005a). At the same time, chronic diseases can push many people and their families into poverty, or deepen their poverty (WHO 2005b).

In European countries, chronic diseases and their causes have a higher concentration among the poor and vulnerable; furthermore, mortality from CVD is declining proportionally faster among the highest socio-economic groups, increasing the health gap between 'haves' and 'have nots' (WHO Europe 2006). A study comparing UK and US data found that in both countries chronic diseases such as diabetes and all types of heart disease were more common among the lowest socio-economic groups (Banks *et al.* 2006), while US research suggests that SES plays a role in explaining racial and ethnic differences in the ability to function once a chronic disease has been diagnosed (Kington and Smith 1997).

With regard to risk factors for chronic disease, a study of 22 European countries found evidence of inequalities in health associated with SES, with worse self-assessed health and higher prevalence of risk factors such as smoking and obesity among lower SES groups (Mackenbach *et al.* 2008). Evidence from the US, Canada and the UK also indicates that obesity is more prevalent among individuals in disadvantaged socio-economic groups (OECD 2007), and Banks and colleagues found that obesity was significantly higher in the US compared with the UK, but in both countries obesity presented a social gradient (Banks *et al.* 2006).

In Australia, a study based on self-reported data on chronic diseases and their risk factors across socio-economic groups showed that there exist social gradients for a number of specific diseases such as diabetes and diseases of the circulatory system, as well as for important disease risk factors such as physical inactivity and smoking (Glover, Hetzel, and Tennant 2004). There is also evidence of area-based inequalities in health: people living in disadvantaged areas are more likely to report poorer health (overall and for specific conditions), and as a result of their poorer health status, they make greater use of GP services (Turrel *et al.* 2006), and have higher admission rates for chronic disease than those living in more advantaged areas (Brameld and Holman 2006). People living in disadvantaged areas are also more likely to engage in behaviours such as smoking, insufficient physical activity or adding salt to meals; and they are more likely to be overweight or obese (Turrel *et al.* 2006). These findings, based on self-reports from the 2001 *National Health Survey* (NHS) (Turrel *et al.* 2006), are consistent with results from two studies conducted in Melbourne that found a difference in BMI among women between SES areas, even after adjusting for individual SES (King *et al.* 2006), and an association between living in more

disadvantaged areas and less likelihood of engaging in physical activity levels conducive to health benefits (Kavanagh *et al.* 2005).

Access issues have been identified in Australia related to both cost and availability of healthy food. The *Healthy Food Access Basket* survey conducted in Queensland in 2006 showed that the cost of healthy food had increased by around 50 per cent (\$148.87) more than the cost of less healthy alternatives (Harrison *et al.* 2010), while another survey conducted in Brisbane showed that respondents from disadvantaged backgrounds were least likely to buy grocery items which were consistent with dietary guideline recommendations, with household income being the greatest discriminator (Turrel *et al.* 2002). Furthermore, qualitative research comparing the dietary behaviours of women living in low, mid and high socio-economic areas, showed that women living in low SES areas tended to report certain eating patterns which were generally less healthy than those reported by those living in high SES areas (Inglis, Ball, and Crawford 2005).

## **Diabetes and disadvantage**

In this section, I present a review of the literature on diabetes, with an emphasis on the link between T2D and disadvantage, and a focus on the literature reporting on lay experiences of disease. Firstly, I set the scene by discussing the definition and types of diabetes, and presenting a review of the literature on the prevalence and burden of disease of diabetes, worldwide and in Australia. I then review the literature on the link between diabetes and disadvantage, focusing on the evidence from high-income countries. I conclude by exploring the literature on the lay experience of T2D, with an emphasis on the literature reporting on research conducted among vulnerable populations in Australia.

### ***Diabetes: An increasing health issue***

Diabetes is a disease marked by hyperglycaemia (high glucose levels) that occurs when the pancreas does not produce enough insulin, or alternatively, when the body cannot effectively use the insulin it produces (WHO 2006; AIHW 2008b). There are three main types of diabetes: type 1 diabetes results from a lack of insulin production, it usually occurs in children, and it is managed with insulin; type 2 diabetes (T2D) results from the body's ineffective use of insulin, and it is the most

common type of diabetes (90 % of people with diabetes worldwide); and gestational diabetes develops during pregnancy in some women and can lead to T2D (WHO 2006; AIHW 2008b).

The object of this study is T2D, the risk factors for which include genetic predisposition and ageing, but also modifiable lifestyle factors which are common to other chronic diseases, such as obesity, physical inactivity and poor nutrition (WHO 2006). T2D affects mostly people 50 years or over, although it is increasingly being diagnosed in children and young people, and it may be managed with changes to diet and exercise, glucose-lowering drugs, insulin injections, or a combination of these (WHO 2006; AIHW 2008b). The model of care for T2D is discussed in detail in Chapter 6.

Risk factors affect the onset of the disease, and also accelerate progression and increase the risk of complications (Tong and Stevenson 2007). If left untreated or uncontrolled, diabetes can lead to serious complications. Short-term complications include: hypoglycaemia (low blood glucose levels); ketoacidosis (build-up of acidic waste in the blood); lactic acidosis (build-up of lactic acid); and bacterial and fungal infections. Long-term complications include: microvascular disease, such as retinopathy (damage to the retina), nephropathy (kidney disease) and neuropathy (nerve disease); and macrovascular disease, such as CHD, stroke and peripheral vascular disease (IDF 2009; AIHW 2008b).

The prevalence of diabetes is increasing worldwide due to ageing, urbanisation, and an increasing prevalence of obesity and physical inactivity (Wild *et al.* 2004). An estimated 180 million people worldwide had diabetes in 2006 (WHO 2006), and projections for 2030 suggest that this figure will more than double to 366 million people (Wild *et al.* 2004). The human costs of diabetes worldwide is significant: in 2005 an estimated 1.1 million people died from diabetes (WHO 2006); however, this figure is likely to underestimate the true burden, because diabetes is known to be underreported on death certificates (Colagiuri *et al.* 2006). About two per cent of people who have had diabetes for 15 years become blind, while about 10 per cent develop a severe visual impairment; diabetes is also the leading cause of kidney disease, and about one third of people with diabetes develop it; and neuropathy affects at least half of all people with diabetes. Finally, diabetes is the most common

cause of amputation which is not the result of an accident, and people with diabetes are 15 to 40 times more likely to require lower-limb amputation than the general population (IDF 2009).

The co-morbidity of diabetes – its co-occurrence with other conditions – highlights the complex nature of this disease. So closely associated is T2D with other conditions, that it has been described as the ‘tip of the iceberg’ representing the Metabolic Syndrome, a cluster of coronary artery disease risk factors including abdominal obesity, hypertension, and dyslipidaemia (abnormal blood lipid levels) (Zimmet 2000). T2D is also referred to as a composite chronic disease associated with diet, physical activity, smoking, dyslipidaemia, hypertension, macrovascular diseases, stress and depression, and SES (Colagiuri *et al.* 2006).

Research measuring outcomes such as ‘impaired physical health days’, ‘impaired mental health days’, and ‘limited activity days’ found that people with diabetes were worse off on every measure of health-related quality of life (Smith 2004). Furthermore, people living with diabetes are twice as likely to have depression as the general population (Anderson *et al.* 2001), while elevated levels of anxiety are common (Grisby *et al.* 2002). In addition to its negative impact on quality of life, depression has been shown to be correlated with poor diabetes management. A study involving 4,463 patients with diabetes showed that major depression was present in 12 per cent of the sample, and was associated with smoking, lack of exercise, and unhealthy eating, and a lower likelihood of adherence to hypoglycaemic agents, and antihypertensive and lipid-lowering medications (Lin *et al.* 2004); while a review of the literature concluded that depression is common among people living with diabetes, and has significant effects on clinical outcomes (Lustman and Clouse 2005). The cross-national *Diabetes Attitudes, Wishes and Needs (DAWN)* study used cross-sectional self-reports involving patients and healthcare providers from 13 countries including Australia, and found that self-management regimen adherence was less than optimal in all countries, and that many diabetes patients suffered from diabetes-related psychological problems and had poor psychological well-being (Peyrot, Rubin, Lauritzen, Snoek *et al.* 2005), with those with more education reporting less diabetes stress (Rubin, Peyrot, and Siminerio 2006).

In Australia, the prevalence of diabetes is also on the increase. According to the latest figures published by the Australian Bureau of Statistics (ABS), an estimated 818,200 Australians, or four per cent of the population, had been diagnosed with diabetes in 2007–08 (ABS 2009), which represents three times the proportion of 1989–90 (AIHW 2008b). These figures, however, are based on self-reported data from the 2007–08 NHS; according to the *Australian Diabetes, Obesity and Lifestyle Study (AusDiab)* – which estimated prevalence on the basis of measured blood glucose levels – an estimated 7.5 per cent of the Australian population had diabetes in 1999–00 (8.0% for males and 7.0% for females) (Dunstan *et al.* 2001). Furthermore, data from the 2005 *AusDiab* follow-up study estimated that 0.8 per cent of Australian adults develop diabetes every year, or 275 adults every day (Barr *et al.* 2006).

Diabetes co-morbidities are also a significant health burden in Australia. It is estimated that the co-morbidity of CVD and diabetes in the non-institutionalised population in Australia in 2004–05 was 2.9 per cent or 417,563; more than 60 per cent of people with diabetes had at least one form of CVD; and, in total, 25.8 per cent of the population had either CVD or diabetes (Tong and Stevenson 2007). Furthermore, chronic kidney disease (CKD) was found in almost half of all patients with T2D consulting their general practitioners (Thomas *et al.* 2006). According to figures from 2004–05, people with diabetes were three times more likely to rate their own health as fair or poor than those without diabetes; and they were also more likely to report high or very high levels of psychological distress (AIHW 2008b). Furthermore, a prospective observational study using data from the *Fremantle Diabetes Study* showed that about a third of the sample of 1,273 diabetes patients had depression, and that depression was associated with physical inactivity and diabetes complications (Bruce *et al.* 2005).

The burden of disease of diabetes in Australia is significant. Diabetes is among the top 10 leading causes of death: diabetes was the underlying cause of death in 2.7 per cent of deaths in Australia, and it contributed to another 6.0 per cent of deaths. Overall, diabetes was the eighth cause of burden and injury in Australia in 2003, and was responsible for 5.5 per cent of the total burden of disease measured in DALYs: 85 per cent of the total diabetes burden was due to diabetes *per se*, while the remainder was due to complications such as neuropathy (5%), peripheral vascular

disease (4%), and diabetic foot (3%). Finally, diabetes was treated in over 500,000 hospitalisations in 2004–05 (AIHW 2008b).

Diabetes places a large financial burden on the healthcare system in terms of expenditure on medications, diagnostic services, general practice and community health services, aged care and hospitalisations. The economic burden of diabetes and its complications in Australia in terms of direct healthcare expenditure was \$907 million in 2004–05, or 1.7 per cent of the recurrent health expenditure in that year. As shown in Figure 2.2, hospital services bore the brunt of the total expenditure, with \$379 million (or 41.8% of the total), followed by diabetes-related pharmaceuticals, with \$273 million (30.1%), out-of-hospital medical services, with \$200 million (22.1%), and research, with \$55 million (6.1%) (AIHW 2008b). In addition, the Australian government spent \$114 million on the National Diabetes Services Scheme (NDSS), a national service providing access to products and services needed for diabetes self-management, such as syringes and blood glucose testing strips (AIHW 2008b).

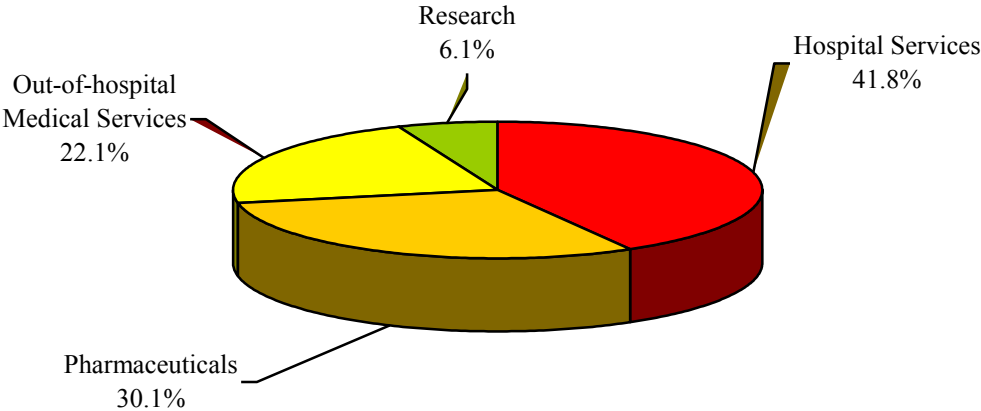


Figure 2.2: Diabetes direct healthcare costs in Australia. Source: AIHW (2008b).

The *DiabCo\$t Australia* study estimated that the average annual cost per person with T2D was \$5,360, of which \$4,260 were direct healthcare costs. As shown in Figure 2.3, hospitalisation, ambulatory services, and medications each accounted for approximately 30 per cent of direct healthcare costs, while consumables such as blood glucose testing and insulin administering equipment accounted for 10 per cent. Insulin and oral hypoglycaemic agents (OHA) accounted for a small proportion of the total costs of medications, with the majority of costs coming from non-diabetes



medications, including lipid and blood pressure lowering agents, non-steroidal anti-inflammatory drugs, and anti-depressant agents (Colagiuri *et al.* 2003).

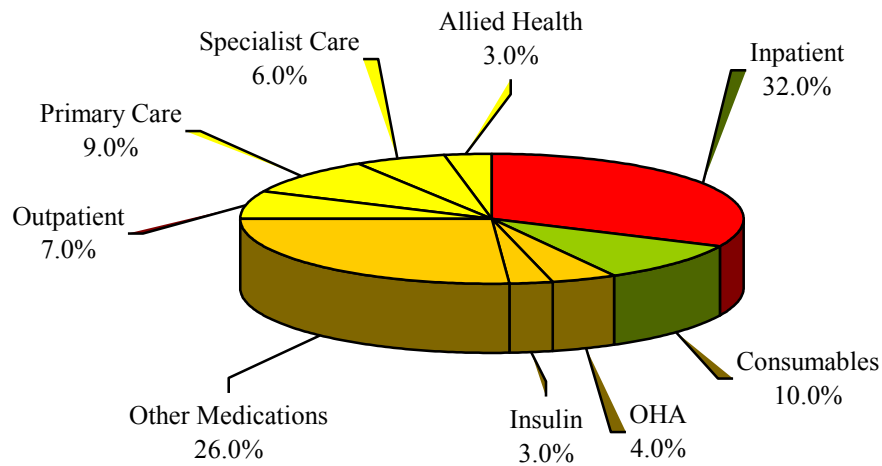


Figure 2.3: Diabetes direct healthcare costs per person. Source: Colagiuri and colleagues (2003).

In addition to direct healthcare costs, the *DiabCoSt* study estimated that the average annual direct non-healthcare cost for people with T2D was \$1,065 per person, with the main contributors being home support, special foods and transport. Finally, indirect costs, including lost wages per patient and carer, made a relatively small contribution, averaging \$35 per person per year, although lost wages per carer were significantly impacted by the presence of macrovascular complications (Colagiuri *et al.* 2003).

### ***The link between diabetes and disadvantage***

Diabetes is not equally distributed within populations. Diabetes, and more specifically T2D, is a clear example of how chronic disease and disadvantage interact, and may serve as a model condition for evaluating the association between socio-economic disadvantage and health status (Brown *et al.* 2004). People at a socio-economic disadvantage are at a greater risk of engaging in specific behaviours and being affected by certain lifestyle and environmental factors that put them at higher risk of developing T2D; once they have developed diabetes, they are less likely to access health services for the management of their condition, and have therefore worse clinical outcomes and poorer quality of life (Goyder, Botha, and

McNally 2000). This constitutes a cycle of diabetes disadvantage, as illustrated in Figure 2.4:

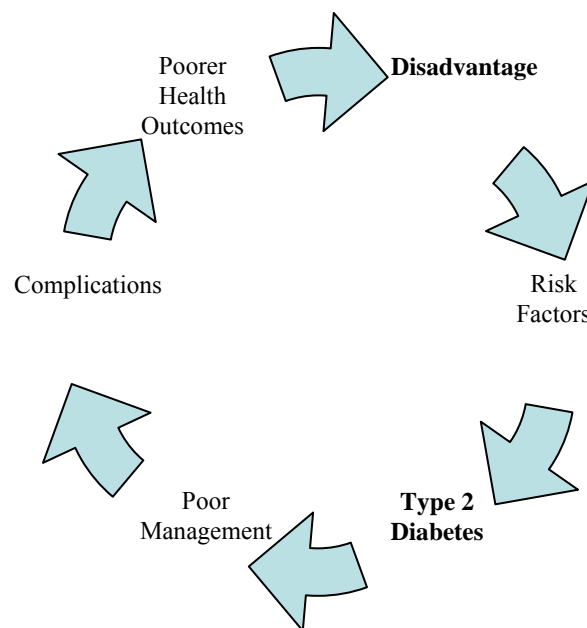


Figure 2.4: The cycle of diabetes disadvantage

Epidemiological studies conducted in the US (Robbins, Vaccarino, and Kasl 2001), the UK (Kumari, Head, and Marmot 2004) and Spain (Larrañaga *et al.* 2005), among other high-income countries, show that the prevalence of diabetes is inversely related to socio-economic position, with the highest prevalence among those in the lowest SES groups. A study conducted in Scotland examined the relationship between socio-economic area-deprivation and T2D, and explored whether the incidence was raised or lowered if surrounding areas were more or less deprived. Results showed that places surrounded by less deprived areas had a lower incidence than expected, whereas those surrounded by more deprived areas had a higher incidence than expected, leading the authors to suggest that the results were more consistent with a neo-materialist explanation of health inequalities than a psychosocial explanation (Cox *et al.* 2007).

Diabetes complications are also more common in low SES groups, and a review of the literature of the complication rates of T2D among indigenous peoples from the US, Canada, Australia, New Zealand and the Commonwealth of the Northern Mariana Islands showed a disproportionate burden of disease complications among

all indigenous peoples regardless of their geographic location, and also greater mortality rates (Naqshbandi *et al.* 2008).

With regard to health behaviours related to diabetes self-management, US research found that African American race and lower levels of education were the strongest correlates of poor control (Selby *et al.* 2007); while another study showed significant differences in engaging in exercise among diabetic women by race, even after adjusting for socio-economic differences, with African American women significantly less likely to engage in moderate physical activity (Egede and Poston 2004). Also in the US, results from the *Translating Research Into Action for Diabetes (TRIAD)* study showed that perceived neighbourhood problems was associated with current smoking and poor control of blood pressure among diabetic patients (Gary *et al.* 2008), while a study analysing the foods sold in shops showed disparities in the availability of healthy foods, with the wealthier suburbs having three times more desirable stores carrying recommended healthy food items for people with diabetes (Horowitz *et al.* 2004).

Finally, a US study exploring the effects of perceived discrimination on service utilisation by diabetes patients using quantitative data from a national health survey found that perceived racial/ethnic discrimination by healthcare providers was associated with lower rates of haemoglobin and blood pressure testing and foot exams (Ryan, Gee, and Griffith 2008).

In Australia, Indigenous people, people from lower socio-economic groups, people from remote and very remote areas, and people born overseas are more susceptible to diabetes (AIHW 2008b). Figures from the *Diabetes: Australian Facts 2008* report published by the AIHW show stark inequalities in the occurrence of disease and in clinical outcomes among Indigenous people: the prevalence of diabetes is estimated to be over three times that of non-Indigenous people; the death rate from diabetes is almost 12 times that of the non-Indigenous population; and death rates from renal complications are 19 times higher. Incidence of T2D is also much higher among Indigenous young people than among non-Indigenous young people, with incidence estimated to be six times higher in NSW (12.7 per 100,000 compared with 2.1 per 100,000) (Craig *et al.* 2007). Diagnosis at younger ages is significant, as earlier onset brings many years with the disease and, thus, an increased risk of experiencing the

full range of micro- and macrovascular complications while relatively young (Alberti *et al.* 2004). Recently, Norman and colleagues published the results of a study reviewing the trends for diabetes-related complications in Western Australia (WA) for the period 2000–08 and found that among those aged 25 to 49 years with diabetes, minor amputations – toe or foot – were 27 times more likely, and major amputations – above or below the knee – were 38 times more likely in Indigenous than in non-Indigenous people (Norman *et al.* 2010). In addition, Indigenous Australians access diabetes self-management education (DSME) less than non-Indigenous Australians, and they demonstrate lower diabetes knowledge (Bruce *et al.* 2003).

Among the lower SES groups, diabetes prevalence and death rate are nearly twice as high for those in the most disadvantaged quintile than for those in the least disadvantaged (AIHW 2008b). These figures are consistent with research on the socio-economic gradient across a number of chronic diseases in Australia, which found that diabetes is the chronic disease with the greatest gradient, with prevalence in the most disadvantaged quintile 2.28 times that of the least disadvantaged quintile for adults aged 25 to 64 years (Glover, Hetzel, and Tennant 2004). This excess prevalence in disadvantaged groups correlates with an inequality in the prevalence of specific risk factors associated with diabetes: a higher proportion of people in the lowest SES groups are overweight or obese, and physically inactive, compared with people in the highest SES groups (AIHW 2008b). Once a diagnosis of T2D is confirmed, the cycle of disadvantage continues. A study using quantitative data from the 2002–03 *NSW Health Survey* showed that relatively disadvantaged people with T2D reported greater health care needs, which were not reflected in access to and use of health services (Comino *et al.* 2006). Diabetes patients in the lower SES groups are more likely to be hospitalised for all complication types, and more likely to die as a result of those complications; and during the period 2003–05, people in the lowest SES group died from T2D at 1.7 times the rate of people in the highest group (AIHW 2008b).

Culturally and Linguistically Diverse (CaLD) communities in Australia are also more likely to report having diabetes than the general population, with people of South Pacific, Middle Eastern, North African, Asian and Mediterranean background showing higher prevalence, hospitalisations and mortality rates (Thow and Water

2005); and people from remote and very remote areas are also more susceptible to diabetes – largely due to the large proportion of Indigenous population in those areas – and diabetes hospitalisation and death rates increase with increased remoteness (AIHW 2008b).

Thus, there exists compelling evidence of an association between SES and diabetes both internationally and in Australia; however, the pathways through which SES and health are related is still poorly understood (Brown *et al.* 2004).

### ***Lay experience of disease: Living with type 2 diabetes***

A diagnosis of diabetes brings major changes to an individual's daily life (Hernandez 1995), and one of the greatest challenges faced by the person with diabetes is managing their disease while maintaining a desired quality of life (Utz *et al.* 2006). Thus, it is essential to examine the disease from the perspective of the person living with it, in addition to that of the health professional (Hernandez 1995). In this section, I review the literature on the lay experience of T2D, with an emphasis on the exploration of the impact of socio-economic disadvantage on the experience of disease and disease management, and a particular consideration of the research conducted in Australia.

Qualitative studies on the lay experience of T2D have examined a broad range of topics including: the experience of diagnosis (Parry *et al.* 2004); lay theories of causality (Mercado-Martinez and Ramos-Herrera 2002; Lawton *et al.* 2007; Daniulaityte 2004); the exploration of the role of social support (Carter-Edwards *et al.* 2004; Loader *et al.* 2002); patient empowerment (Stone *et al.* 2005); and the experience of diabetes services and medical management (Pooley *et al.* 2001; Lawton *et al.* 2006a; Nair *et al.* 2005). Ethnographic research has also investigated the issue of compliance, and the social and cultural referents shared by clinicians and patients during the clinical encounter (Ferzacca 2000). However, much of literature reviewed has focused on the experience of and attitudes towards self-management, comparing the experiences and attitudes between individuals with good and poor control (Savoca, Miller, and Quandt 2004; Garcia de Alba Garcia *et al.* 2007); identifying perceived barriers and facilitators (Nagelkerk, Reick, and Meengs 2006; Utz *et al.* 2006) and psychosocial issues affecting self-management (Caban *et al.* 2008); exploring issues of causation and control (Parry *et al.* 2006); or investigating

specific aspects of self-management such as exercise (Lawton *et al.* 2006b) and self-monitoring of blood glucose (Peel, Douglas, and Lawton 2007).

A US study exploring the barriers and facilitators to self-management among rural African Americans found that the cost of medication and supplies, fitting the complex self-management regimen into everyday life, and dealing with stress were the main barriers to self-management, while accessible diabetes education and psychosocial support were perceived as needed (Utz *et al.* 2006). Participants in this study also identified the importance of ‘taking control’ to be successful in managing diabetes (Utz *et al.* 2006), which is consistent with research conducted among urban Latinos living in New York (Caban *et al.* 2008), and in a small sample of adults living with T2D in New Zealand (Handley, Pullon, and Gifford 2010).

Also in the US, Savoca and colleagues investigated the experiences and attitudes of people at the extremes of glycaemic control and found that those at the lowest end of glycaemic control were mostly African Americans, had low levels of education and were in the lowest income category, and most reported diabetes complications. Among these participants, issues of emotional and financial distress, depression, and lack of control over the circumstances of everyday life were common (Savoca, Miller, and Quandt 2004), supporting findings from research conducted among low-income earners in Mexico (Mercado-Martinez and Ramos-Herrera 2002; Daniulaityte 2004), urban Latinos in New York (Caban *et al.* 2008), and Pakistani and Indian immigrants in the UK (Lawton *et al.* 2007).

Emotional distress has been found to be a major theme in the cultural model of diabetes causation in working class neighbourhoods in Mexico, where the onset of diabetes is commonly attributed to distressful life circumstances leading to emotional states such as *susto* – a ‘deep sudden unexpected fright’ (Daniulaityte 2004, 1905) – or anger (Daniulaityte 2004; Garcia de Alba Garcia *et al.* 2007; Mercado-Martinez and Ramos-Herrera 2002). In the UK, Lawton and colleagues compared the perceptions and understanding of disease causation between Pakistani and Indian immigrants and British-born respondents. The authors found that Pakistani and Indian immigrants attributed their disease to external factors – most commonly linking their diabetes onset to their migration to Britain – and their accounts tended to convey a sense of lack of control over, and responsibility for, their own health. In

contrast, the notion of personal responsibility was central to the accounts of most British-born respondents, who presented themselves as being to blame for their disease (Lawton *et al.* 2007). These findings are consistent with other research conducted in the UK, which found that explanations of causation were linked to participants' own perceived role in management: those who emphasized lifestyle in disease causation saw themselves as responsible for disease management, while those who emphasized genetic factors surrendered responsibility and control for their disease to health professionals (Parry *et al.* 2006).

Although Utz and colleagues found that psychosocial support from family and friends was perceived as a facilitator to self-management (Utz *et al.* 2006), a study exploring the role of social support among African American women found that participants felt that their families did not understand their life with diabetes (Carter-Edwards *et al.* 2004). Similarly, research conducted among Latinos found that women generally reported not feeling supported by others, including their family members; however, men were more likely to report receiving support from their spouses (Caban *et al.* 2008).

With regard to the quality of diabetes medical care, a UK study found that lack of consultation time underpinned the concerns of both patients and health professionals: lack of time was seen to fragment care, leading to inadequate consultations which did not address the individual needs of the patient (Pooley *et al.* 2001). These findings are consistent with US research exploring the views of a rural sample, which found that lack of individualised and coordinated care was perceived as one of the main barriers to self-management, while developing a collaborative relationship with the healthcare provider was seen as the most effective strategy (Nagelkerk, Reick, and Meengs 2006). Finally, research conducted among Pakistani and Indian immigrants in the UK (Lawton *et al.* 2006a; Lawton *et al.* 2006b) highlighted the need for health professionals to deliver culturally-appropriate advice, supporting the findings of a Canadian study which included participants of First Nations descent (Nair *et al.* 2005).

In Australia, the relatively small body of literature reporting on the lay experiences of people living with T2D has tended to focus on the exploration of perspectives on clinical care (Tabrizi *et al.* 2007; Shortus *et al.* 2007; Wellard, Rennie, and King

2008); the evaluation of intervention programs (Abbott *et al.* 2010; Tyrrell *et al.* 2003) and the exploration of the experience of disease among Indigenous Australians (Thompson and Gifford 2000; Dussart 2009; Tamwoy *et al.* 2004); and, to a lesser extent, the experience of diabetes among immigrant populations (Manderson and Kokanovic 2009; Kokanovic and Manderson 2006; Oliver *et al.* 2007). Qualitative research has also explored the language used by people living with T2D, finding that frequent references to ‘control’ form a central part of the moral discourse surrounding diabetes (Broom and Whittaker 2004).

Research conducted among vulnerable populations, including Warlpiri people in Central Australia (Dussart 2009), an urban Aboriginal community in Melbourne (Thompson and Gifford 2000), and Pacific Islanders in the Illawara region (Oliver *et al.* 2007) found that diabetes is commonly attributed to lifestyle changes and settled life. In their exploration of the meaning of health and diabetes in an urban Aboriginal community, Thompson and Gifford noted that while the ‘sugar’ causing diabetes was seen as coming from outside the community, thus disconnecting land and kin, it was also viewed as an important cultural food passed down through the generations, thus connecting family and community (2000). A study conducted among Torres Strait Islanders in the Northern Peninsula found that diabetes was perceived not as an individual illness, but rather as a reflection of a broader sickness experienced by the community (Tamwoy *et al.* 2004), and supports the views of participants in Thompson and Gifford’s ethnographic study, who experienced diabetes as an illness resulting from the lack of balance people experience in their everyday lives, further reinforcing their experience of having little control over their future (Thompson and Gifford 2000).

Research conducted in metropolitan Melbourne among Greek, Chinese, Indian, and Pacific Islander Australians living with T2D found that worry and distress were common among participants, and diabetes was experienced as simply one of the numerous events interfering with their sense of well-being, and their everyday lives. A model of distress as a negative feedback loop was observed: everyday circumstances led to stress, which led to or complicated pre-existing diabetes, which, in turn, triggered further stress (Manderson and Kokanovic 2009). Worries and concerns, and high levels of stress partly triggered by the inability to fulfil family and cultural roles were also identified by Thompson and Gifford (2000) and by Abbot



and colleagues in their evaluation of a cooking course for Aboriginal people with diabetes in Western Sydney (2010), and, in both cases, the unpredictability of family and community life was found to be a barrier to diabetes management (Abbott *et al.* 2010; Thompson and Gifford 2000).

Family and cultural environments have also been found to influence attitudes towards diabetes self-management. Participants in Abbott and colleagues' study viewed eating alone or having special meals as isolating and undesirable (2010), supporting results from an ethnographic study on diet and diabetes among Warlpiri people, which also found that, despite being diabetic-unfriendly, store-bought prepared meals were perceived as the most convenient, as they could be easily shared in a demand-sharing economy (Dussart 2009). Exercising for one's individual health was also found to be selfish and hence shameful in an urban Aboriginal community (Thompson and Gifford 2000), and similar views were found among Torres Strait Islanders, who generally discussed physical activity in terms of the barriers involved, and attributed their decreased physical activity to the dramatic decline of gardening, a tradition among their communities (Tamwoy *et al.* 2004).

Research exploring the experience of diabetes among vulnerable populations has also found evidence of the impact of socio-economic disadvantage on attitudes towards self-management. Food affordability was identified as a barrier to adopting a healthier diet among urban Aboriginals attending a cooking course in Western Sydney (Abbott *et al.* 2010), while Oliver and colleagues, in their evaluation of an intervention program developed for immigrant Pacific Islanders living with diabetes, noted that participants lacked 'important skills including money management, budgeting and planning, which are particularly necessary for low-income Australians' (2007, 108). Furthermore, Jeon and colleagues explored the economic hardship faced by a sample of 66 patients with chronic disease including diabetes, and found that the economic impact of chronic illness affected participants' ability to afford necessary medical care and treatments, and engage in recommended self-management practices such as access to healthy food, exercise and gym memberships, and social activities (Jeon *et al.* 2009).

Support from family was found to encourage lifestyle changes in an urban Aboriginal community, whereas family resistance or lack of support was experienced

as a barrier to adopting a healthy diet (Abbott *et al.* 2010). A study exploring immigrant women's views on social support found that participants gave ambivalent accounts of support from family members. While most women reported receiving support from their families in some aspect of self-management, they often felt alone and not understood, and some sought the emotional support provided by others with diabetes, including through diabetes support groups (Kokanovic and Manderson 2006), which were also perceived as needed by Torres Strait Islanders in Tamwoy and colleagues' study (2004).

With regard to medical care, a study by Tabrizi and colleagues explored the needs, expectations, and experiences of people living with diabetes on the quality of care received. The authors found unanimous consensus about the importance of self-management education and information, and practical information about nutrition and diet; and a high degree of consensus about the importance of good communication with their clinicians, while continuity of care was seen as a high-priority issue for some, but not all participants (Tabrizi *et al.* 2007). Participants in Tabrizi and colleagues' study – a sample of 33 registered members of Diabetes Australia – did not consider consultations to be under time pressure (2007); this finding contrasts with research exploring doctor-patient communication in immigrant Australians with T2D (Kokanovic and Manderson 2007), and consumers' and health professionals' perspectives on adherence to multiple medications in diabetic kidney disease (Williams, Manias, and Walker 2008), which found that lack of consultation time was perceived as not allowing for a trusting relationship between patient and health professionals to develop and preventing individualised care.

A study involving general practitioners (GPs), allied health professionals (AHPs), endocrinologists and adults with T2D explored how multidisciplinary care plans for diabetes are used, and found that they rarely result in collaboration between care providers as envisaged in care planning policy. The study results suggested that care planning facilitated referrals to AHPs; however, the study found that patients had limited recollection about their care plans, while AHPs felt sceptical about their benefits (Shortus *et al.* 2007). Furthermore, a study exploring consumers' experiences with T2D medicine information found that the level of understanding of prescribed medicines was generally poor, and participants reported having received minimal information about their medicines from their doctors and pharmacists (Lee

2007); these results are consistent with a study exploring the perspectives of people with chronic kidney disease, which found that inadequate knowledge about the actions of medication was a barrier to medication adherence, as were the cost of multiple medications and poor general well-being (Williams, Manias, and Walker 2008).

Finally, although not exploring the lay experience of disease, an exploratory study examined GPs' views on how socio-economic position impacts on diabetes management and found some evidence of negative stereotyping. Respondents – nine GPs practicing in low SES areas – identified low health literacy, poverty and psychosocial issues, and negative attitudes towards health as barriers to diabetes management; and suggested two strategies for improving diabetes management among disadvantaged patients: providing educational materials that matched literacy levels, and implementing financial incentive schemes to encourage patients to participate in diabetes management (Rose, Harris, and Ho 2004).

Although the need to research the impact of limited socio-economic resources on diabetes management has been noted (Rose 2005), no qualitative studies were found in the literature reviewed that explored how people across the spectrum of socio-economic disadvantage living with T2D in Australia experience their disease, and how disadvantage might influence self- and clinical management.

## **Conclusion**

In this chapter, I reviewed the literature relevant to the philosophical and theoretical underpinnings of the study. The notion of social justice as it relates to health equity was explored first, and was presented as the justification for adopting a social determinants of health approach to tackling health inequities. A broad literature review explored the link between chronic disease and disadvantage, and led to the discussion of the inequities surrounding the prevalence and clinical outcomes of T2D in Australia.

A review of international and Australian literature reporting on the lay experience of T2D among vulnerable populations highlighted issues of poverty, distress and lack of control, and revealed the impact of socio-structural and cultural factors on the experience of and attitudes towards disease and disease management. The review of

the literature also revealed that the relatively small body of literature reporting on the lay experience of T2D among vulnerable populations in Australia has focused on Indigenous and immigrant Australians, and found no study exploring the experiences of people across the spectrum of socio-economic disadvantage.

## Chapter 3 – Conceptual Framework

*If your only tool is a hammer, all your problems will be nails.*

(Mark Twain)

### **Social determinants of health**

The overarching theoretical underpinning of the study is a conceptual framework adopted by WHO's Commission on Social Determinants of Health (CSDH). The development of this conceptual framework fitted within the established understanding of the impact of social and political conditions on health, and drew from the mounting evidence on the scope of health inequalities (see Chapter 2). Historically, it followed the debates and national inquiries sparked by *The Black Report* through the 1980s and early 1990s, and the adoption of health equity and the SDH as explicit policy concerns by a growing number of countries by the late 1990s and early 2000s (Solar and Irwin 2007). The framework was the object of a discussion paper first published in 2005, and updated in 2007 (Solar and Irwin 2007); and an amended version was adopted by the CSDH in its final report to WHO entitled *Closing the gap in a generation: Health equity through action on the social determinants of health* (CSDH 2008).

The CSDH conceptual framework is grounded on the notion that strengthening health equity means going beyond concentrating on the immediate causes of disease, and focusing on the 'causes of the causes' – 'the fundamental global and national structures of social hierarchy and the socially determined conditions these create in which people grow, live, work, and age' (CSDH 2008, 42). The framework comprises three elements which help explain the distribution of health and well-being between and within countries (see Figure 3.1) (Solar and Irwin 2007; CSDH 2008).

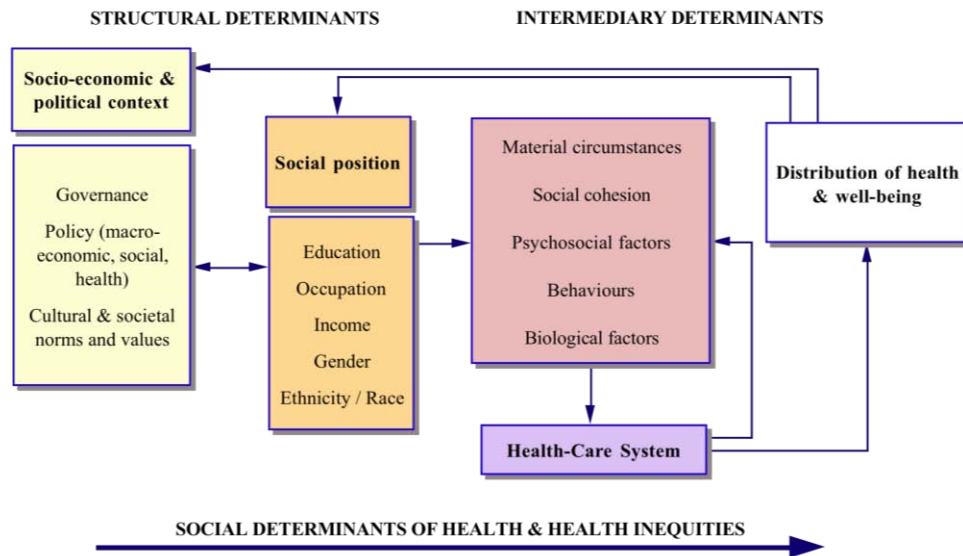


Figure 3.1: CSDH conceptual framework. Source: Adapted from CSDH (2008) and Solar and Irwin (2007).

The first element of the framework is the socio-economic and political context, a broad set of structural, cultural and functional aspects of a social system which exert a powerful influence on patterns on social stratification and, thus, on people’s health opportunities. This broad structural context includes governance, or the way in which a society organises itself to make and implement decisions; macroeconomic policies such as those regulating the labour market structure, and social and health policies; and cultural and societal norms and values, which inform the value placed on health and the degree to which health is seen as a collective social concern (Solar and Irwin 2007).

The second element of the framework is ‘social position’, a term adopted by CSDH (2008) instead of ‘socio-economic position’ (SEP) – the term originally adopted by Solar and Irwin (2007). SEP is an aggregate concept that captures people’s position in the social stratification system and which can be measured at individual, household and neighbourhood level, and at different points of the lifespan. Major variables used to operationalise SEP include: income, education and occupation, which are proxies used to measure social stratification; gender, a concept referring to those characteristics of women and men which are socially constructed; and race or ethnicity, as constructs which can form the basis of social divisions and discriminatory practices (Solar and Irwin 2007). ‘Social class’ was included by Solar

and Irwin as a distinct component of SEP in their conceptual framework (2007), but did not appear on the version adopted by the CSDH in its final report (2008).

The structural determinants operate through a series of intermediary determinants, which constitute the third element of the CSDH framework. These intermediary social factors flow from the configuration of underlying social stratification, and, in turn, determine differences in exposure and vulnerability to risk factors. The main categories of intermediary determinants of health are: material circumstances, which include determinants linked to the physical environment, such as housing, consumption potential, and the working and neighbourhood environments; social cohesion; psychosocial circumstances, including psychosocial stressors, stressful living circumstances, social support, and coping styles; behaviours, including smoking, diet, alcohol consumption, and physical exercise; and biological factors, such as genetic markers, age and sex. Finally, the healthcare system itself is included as an independent determinant, highlighting the role healthcare systems should play in reducing health inequalities, not only by providing equitable access to services, but also by implementing public health programs which improve the health of disadvantaged groups (Solar and Irwin 2007; CSDH 2008).

In their discussion paper, Solar and Irwin draw attention to the difference between ‘social determinants of health’ and ‘social determinants of health inequities’: the former refer to the social factors which promote and undermine the health of individuals and populations, while the latter are the social processes underlying the unequal distribution of these factors (Solar and Irwin 2007). Thus, in the authors’ conceptual framework, the more upstream elements – socio-economic and political context, and SEP – are structural determinants and constitute the social determinants of health inequities; and the more downstream element – the intermediary determinants – constitute the social determinants of health (Solar and Irwin 2007). In its final report to WHO, CSDH does not distinguish between these two notions, and adopts, instead, a holistic interpretation of the SDH encompassing both the conditions of daily life and the structural drivers (CSDH 2008). This broad interpretation is that adopted in this study.

This study draws from the literature on SDH and theories of disease distribution, and adopts a neo-materialist interpretation of the way in which SDH operate. Although

the theoretical underpinning of the study draws from elements from the psychosocial perspective – in particular, some aspects of social networks theories – the emphasis is on the impact of differential material and structural circumstances on health and illness. Consistent with a neo-materialist interpretation, the study is underpinned by the understanding that at a microlevel, socio-economic deprivation results in fewer social and material resources, leading to poorer health outcomes; and at a macrolevel, deprivation results in social disinvestment, that is, less investment in social and environmental conditions necessary for promoting health (Solar and Irwin 2007).

## **Social networks and health**

Health and illness are cultural constructs, and people experience them not in isolation, but, rather, in social and cultural settings. Thus, this study is underpinned by the understanding that an individual's experience of disease is impacted by their social environment, and draws from elements of Berkman and Glass conceptual model of how social networks impact on health (2000).

The authors postulate a cascading causal process from upstream macrosocial factors to psychosocial mechanisms which impact health through specific pathways (see Figure 3.2). At a macrolevel, social and structural conditions provide the context in which social networks are embedded. These conditions include cultural, socio-economic and political factors, as well as conditions derived from rapid social change, such as urbanization, conflict or civil unrest, and economic depression (Berkman and Glass 2000).

These upstream macrosocial forces condition the shape and nature of social networks – the webs of social relationships surrounding the individual and the characteristics of those ties. Social networks operate at a mezzo or intermediary level, and their structure and the characteristics of their network ties provide opportunities for more downstream mechanisms to operate (Berkman and Glass 2000).



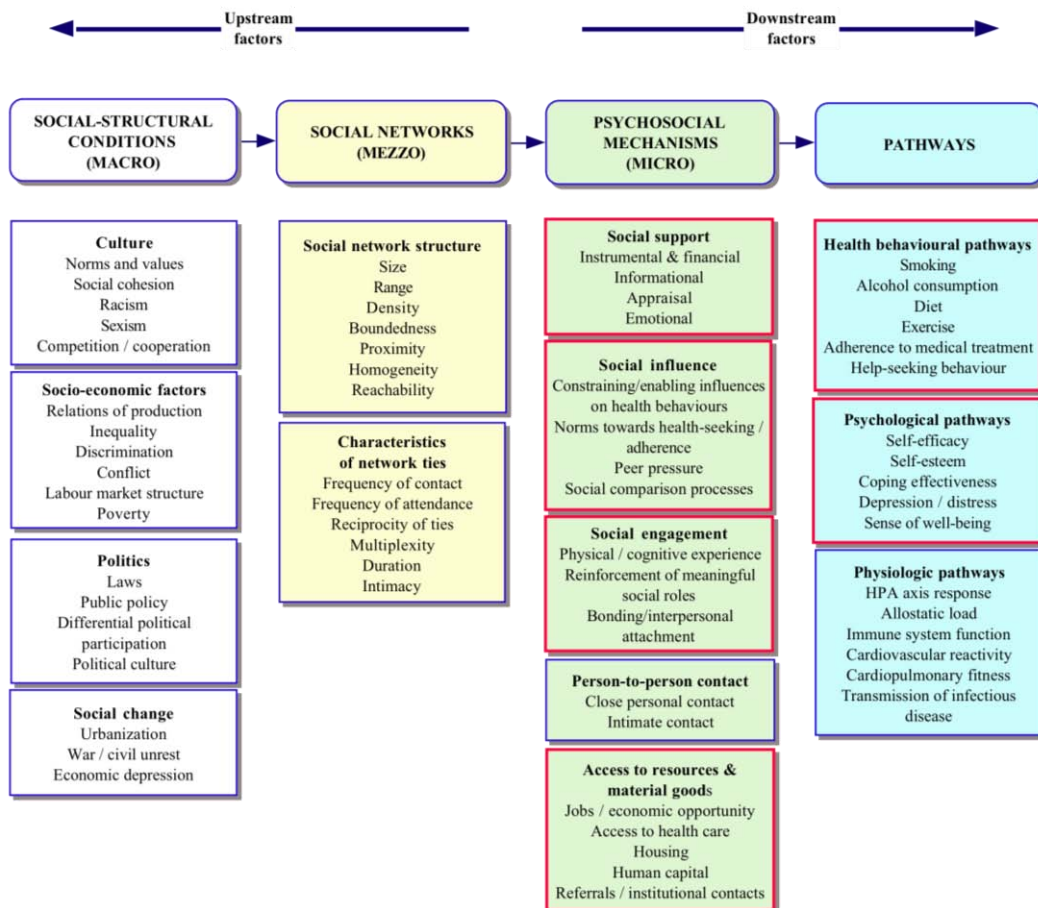


Figure 3.2: Conceptual model of how social networks impact on health (relevant elements highlighted). Source: Adapted from Berkman and Glass (2000).

Berkman and Glass posit that social networks impact on health through psychosocial mechanisms operating at a microlevel. In particular, social networks influence health via the provision of four different kinds of support: emotional support relates to the caring, sympathy and understanding, and/or esteem or value available from others (Thoits 1995), and is most often provided by an intimate other; instrumental support refers to help or assistance with tangible needs, including financial support; information support is related to the provision of advice or information regarding particular needs; and appraisal support relates to ‘help in decision making, giving appropriate feedback, or help deciding which course of action to take’ (Berkman and Glass 2000, 145).

Social networks also influence health through social influence, constraining or enabling health behaviours. Shared norms around specific health behaviours, for example alcohol or tobacco consumption, dietary patterns, treatment adherence and

healthcare utilisation, can be the sources of social influence resulting in direct health consequences for the behaviours of network members (Berkman and Glass 2000).

Social engagement is another pathway through which social networks may influence health. By providing opportunities for engagement and participation, social networks define and reinforce social roles, including parental, familial, occupational, and community roles; and provide opportunities for companionship and sociability, which are not the result of the provision of support, but are the consequence of participation in a meaningful social context (Berkman and Glass 2000).

Berkman and Glass posit that social networks also operate through providing differential access to material goods, resources and services, including access to health care, and referrals and institutional contacts. The authors speculate that participation in networks on the basis of shared work experience, health experiences or religious affiliation, for example, provides access to resources and services which go beyond the social support provided by these ties, and affect health outcomes (Berkman and Glass 2000). Finally, although outside of the scope of this study, networks also influence health status and disease through person-to-person contact by restricting or promoting exposure to infectious disease (Berkman and Glass 2000).

The final element of Berkman and Glass' conceptual model is the specific proximal pathways through which psychosocial mechanisms impact on health. The authors distinguish three types of pathways: health behaviours, such as tobacco and alcohol consumption, physical exercise, dietary patterns, illicit drug use or sexual behaviour; psychological mechanisms, such as self-efficacy – defined as the degree of confidence a person has in their ability to perform specific behaviours, self-esteem, coping mechanisms, mood, and perceived well-being; and specific physiologic pathways through which the impact of social relationships is expressed, for example, the link between social support and changes in the function of the immune system (Berkman and Glass 2000).

This study is especially concerned with the microlevel psychosocial mechanisms which result from social networks; how these translate into specific health behavioural and psychosocial pathways; and the way in which social networks may

provide access opportunities to resources and material goods, including access to healthcare and support services (see highlighted elements in Figure 3.2).

## **Socio-economic position and diabetes**

This study explores the impact of socio-economic disadvantage on the experience of disease among persons with diabetes, and draws substantially from a disease-specific conceptual framework of the mechanisms through which SEP influences health developed by Brown and colleagues (2004).

The authors argue that despite the compelling evidence for the association between low SEP and adverse health outcomes, the pathways linking SEP and health in persons with diabetes and other chronic conditions are still poorly understood (Brown *et al.* 2004). Furthermore, because of the strong social gradient present in the distribution of diabetes, and following the work of Glasgow and colleagues (1999), and McKinley and Marceau (2000), the authors state that diabetes is a ‘model condition for evaluating the associations between SEP and health among persons with chronic disease’ (2004, 63). Based on an extensive review of the literature on diabetes, Brown and colleagues propose a conceptual framework describing pathways which illustrate the relation between SEP and health outcomes among persons with diabetes (see Figure 3.3), and present the evidence supporting each of the pathways.

In the model, the notion of SEP encompasses current individual socio-economic status (SES) and also community-level characteristics, and takes into account the cumulative effects of time. With regard to health outcomes, the authors consider both general and diabetes-specific outcomes. Indicators of general health outcomes include health status, quality of life and mortality; and diabetes-specific outcomes include intermediate outcomes such as glycaemic control, lipid management, blood pressure and medication management, and long-term consequences such as cardiovascular disease, retinopathy, nephropathy, cerebrovascular disease, and peripheral vascular disease. In addition, the authors acknowledge the existence of three important covariates which should be considered in any analysis of the relation between SEP and health: age, sex, and race or ethnicity (Brown *et al.* 2004).

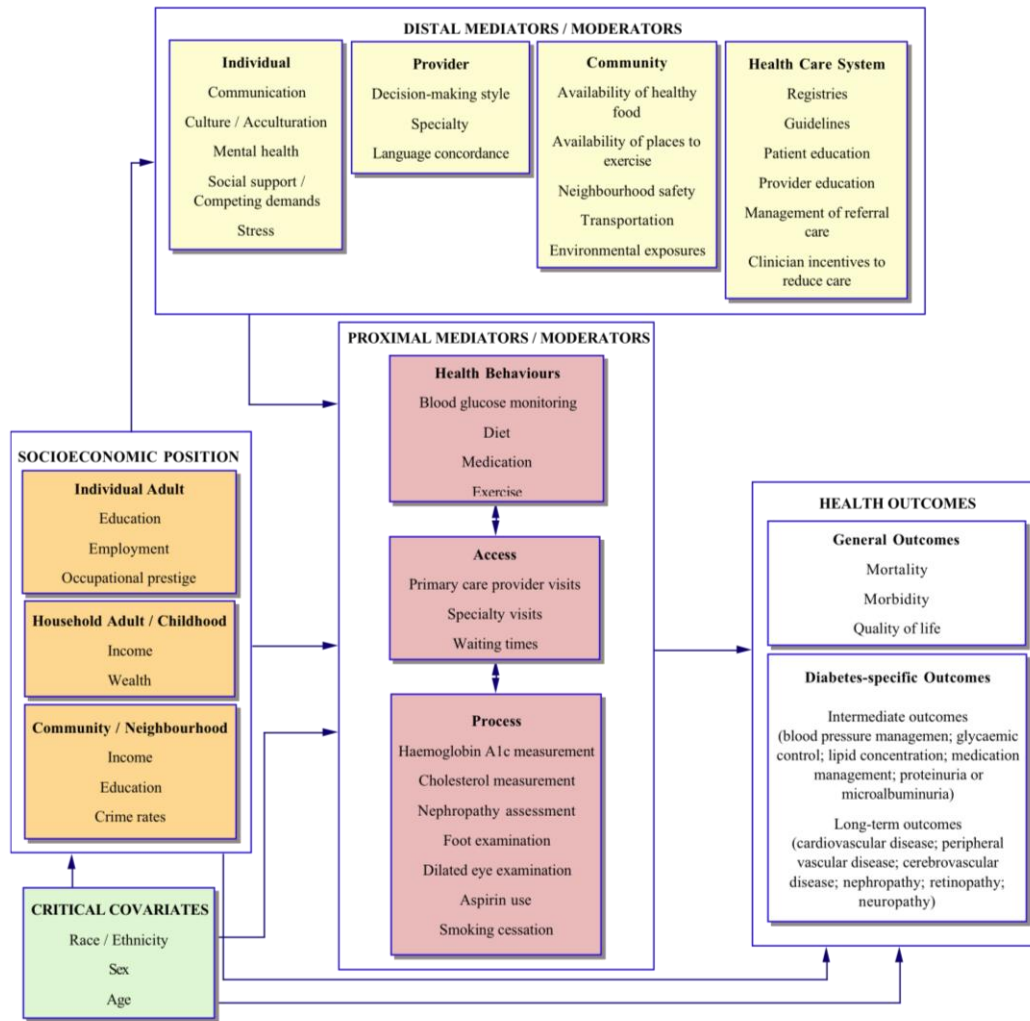


Figure 3.3: Conceptual framework for the relation between socio-economic position and health among persons with diabetes. Source: Brown and colleagues (2004).

In their proposed conceptual framework, the authors posit that two sets of mechanisms influence the relation between SEP and health in persons with diabetes: proximal factors and distal factors. Proximal factors are the main mechanisms, and include: health behaviours, access to care, and process of care. Distal factors are individual, community, healthcare provider and healthcare system characteristics which potentially explain the relation between SEP and health behaviours, access and process, and health outcomes for persons with diabetes. Both sets of factors are called ‘mediators’ if they are the means through which SEP influences health outcomes, or ‘moderators’ if the effect of SEP varies according to levels of the factors (Brown *et al.* 2004).

## ***Proximal mediators/moderators***

Brown and colleagues posit that SEP may influence health outcomes among persons with diabetes through three proximal factors: individual health behaviours; access to care; and process of care (2004).

### **Health behaviours**

Persons with diabetes must adopt a complex set of health behaviours, including glucose self-monitoring, adherence to medication and recommended diet, exercise, and smoking cessation. The authors refer to the evidence linking low SEP with higher rates of smoking, lower rates of blood glucose monitoring and lower rates of vigorous exercise. However, they point out the need for further research into the complex range of self-management behaviours persons with diabetes are required to adopt to manage their glucose and lipid levels, blood pressure and associated chronic conditions (Brown *et al.* 2004).

### **Access to care**

This element encompasses both the availability and actual use of healthcare services, that is, potential access and realised access. Brown and colleagues propose that access to care can be measured using indicators including: identification of a regular source of care; number of primary care visits; ease of specialist referrals; number of specialist visits; travel time to appointments; and appointment waiting times (2004).

### **Process of care**

This element refers to the technical and interpersonal care provided to patients within the healthcare setting. Among the important processes of care for diabetes patients, the authors highlight the following: regular measurement of blood pressure, haemoglobin A<sub>1c</sub>, and cholesterol levels; assessment of nephropathy; regular dilated eye and foot examinations; and counselling on smoking cessation (Brown *et al.* 2004). Although the authors do not refer explicitly to the notion of ‘quality of care’, in this study, ‘process of care’ is understood to be concerned with indicators of the quality of care received by persons with diabetes.

## ***Distal mediators/moderators***

The second set of mechanisms posited by Brown and colleagues (2004) to explain the pathways between SEP and health outcomes for persons with diabetes are more distal or upstream factors which include characteristics relating to: the individual with diabetes; the healthcare provider; the community or neighbourhood; and the healthcare system.

### **Individual-level characteristics**

These individual-level characteristics relate to five main domains: patient/provider communication; culture and acculturation; mental health; social support and competing demands; and stress. The effectiveness of patient and provider communication is an important individual-level factor in the model, as Brown and colleagues point out that communication barriers ‘may significantly decrease a patient’s ability to appropriately obtain health care and may inhibit the degree to which the patient benefits from such care’ (2004, 67). The authors highlight that the communication style of the healthcare provider, inadequate functional health literacy, and language discordance are barriers to effective communication of particular salience for persons with diabetes (Brown *et al.* 2004).

Culture and acculturation represent the second individual-level characteristic cited in the conceptual framework. Cultural factors which represent shared norms, values, and attitudes may influence health beliefs, treatment preferences, health behaviours, and, ultimately, health outcomes. The authors point out that it is not clear whether the associations observed in the general population are the same for persons with diabetes due to the limited number of studies exploring the impact of culture or acculturation on health among people with diabetes (Brown *et al.* 2004).

Mental health also influences health outcomes. Depression, eating disorders and other psychological conditions are more common in persons with diabetes; and, in addition, depression may influence self-management behaviours, access to healthcare services and communication with healthcare providers (Brown *et al.* 2004).

Social support and social integration are cited as positively influencing diabetes health outcomes. The authors point to the scarcity of empirical data on how social support influences health outcomes among people with diabetes, and hypothesize

that better self-management skills, improved access to healthcare services, and improved quality of care may play a role. On the other hand, certain types of ties which represent competing demands, either because they entail financial expenditure or because they represent a demand on one's time, may have detrimental effects (Brown *et al.* 2004).

Lastly, stress has been linked to control of blood glucose levels and it may be a mechanism through which SEP and other individual-level variables influence health. Brown and colleagues highlight that much of the research has focused on the acute effects of stress on diabetes management, while the long-term impact of sustained exposure to socio-economic deprivation and its association with detrimental health behaviours remains poorly understood (2004).

### **Provider characteristics**

These are social influences on clinician decision-making, and include: clinician's decision-making style; relationship with the patient; speciality; and the SEP of the patient and the patient's community. Among the evidence supporting this element of the framework, the authors point to US research showing that patients' SEP influences physicians' perceptions of their intelligence and personality characteristics (Van Ryn and Burke 2000), and posit that these perceptions may influence healthcare providers' willingness or ability to provide counselling on healthy behaviours and disease management (Brown *et al.* 2004).

### **Community-level characteristics**

These are characteristics of communities or neighbourhoods, which may influence general health outcomes. Among these characteristics, Brown and colleagues highlight: the availability and accessibility of healthy food; access to places to exercise; neighbourhood safety, which may influence people's ability or willingness to engage in physical activity; transportation, as typically people with diabetes are required to use numerous health services; and environmental exposures (2004).

### **Healthcare organisations**

Lastly, Brown and colleagues discuss characteristics of healthcare systems which have the potential to negatively affect health behaviours, access and process (proximal factors), and, thus, result in worse health outcomes. One of these characteristics is the management of referral care, as restrictions on referrals to

specialists that are differentially applied to persons of low SEP may adversely influence health outcomes. In addition, financial and organisational arrangements – such as patient co-payments and clinician incentives – may result in poorer health outcomes for persons of low SEP (Brown *et al.* 2004).

## **My positioning as a researcher**

Health and illness are value-laden notions, and public health ‘can never be an entirely objective, ‘value-free’ enterprise’ (McKinlay and Marceau 2000, 760). The values which define me as an individual influence my attitudes towards health and its importance, and my beliefs around the role that governments should play in addressing public health issues generally and health inequities in particular.

I believe that health is valuable *per se*, and I also believe that health and well-being are critically important to achieving a sense of independence, autonomy and freedom. Furthermore, I believe that all individuals and groups in society should have the same opportunity to attain the maximum level of health and well-being, expressed as that attained by the most advantaged groups in society.

Although acknowledging some of the utilitarian arguments on the value of achieving health equity, I take the view that addressing health inequities in our society is an issue of social justice which governments should pursue; and I believe that health equity can be construed as a human right articulated as a ‘right to equal opportunities to be healthy’, based on the principles of non-discrimination and equal opportunity.

Finally, I approach public health from a socio-structural perspective, and thus, seek to explain and understand health and healthcare-seeking behaviours within the parameters of the social and structural circumstances in which they take place (Baum 2004). Thus, although I do not hold a determinist view and acknowledge that some health outcomes may ultimately be determined by individual health behaviours, I do not subscribe to more individualistic approaches which place the emphasis on individual responsibility and which often bring with them a culture of blame.



## **Conclusion**

In this chapter, I positioned the study within social and public health theories, describing the three conceptual frameworks upon which the study is based. The study is underpinned by the CSDH framework, and adopts a neo-materialist interpretation of the way in which SDH operate. In addition to this overarching framework, the study draws from elements of a model of how social networks impact on health, and from a diabetes-specific conceptual framework for the relation between SEP and health outcomes.



## Chapter 4 – Methods

*Not everything that can be counted counts,  
and not everything that counts can be counted.*

(Albert Einstein)

### Research design

The research design was informed by the scope of the study's overall aim and objectives and by ethical considerations. The study adopted a qualitative methodology based on a cyclical two-stage design consisting of focus groups followed by in-depth interviews.

### Research questions

The study design and the methodology adopted were developed upon consideration of the aim of the study and its research questions. The overall aim of the study was to explore how persons at socio-economic disadvantage living with T2D experience their disease, and how disadvantage impacts on their disease management. Within this broad research issue, the specific objectives of the study were to:

- 1) Explore the attitudes and experiences of persons at a socio-economic disadvantage living with T2D with respect to:
  - a. living with and self-managing their disease;
  - b. the medical management of their disease; and
  - c. seeking access to healthcare services for the management of their disease;
- 2) Analyse the perceptions of disadvantaged persons living with T2D of the quality of care received, and how these perceptions are formed; and
- 3) Elicit the priorities for the effective management of T2D from the perspective of disadvantaged health consumers.

The scope of the research questions influenced the overall methodology and the specific data collection methods adopted in the study. Furthermore, the consideration of participants' vulnerability due to their position of socio-economic disadvantage influenced the ethical approach underpinning the conduct of the study.

## ***Ethical considerations***

The study was conducted in a manner that upheld the values of respect, research merit and integrity, justice, and beneficence, as established in the *National Statement on Ethical Conduct in Human Research* (National Statement) (NHMRC 2007). In the context of qualitative research, it is difficult to define ethical conduct in advance, as ‘moral questions can arise at any time during the research process’ (Hewitt 2007, 1151). It is, however, essential that the researcher is aware not only of ‘procedural ethics’ – which involves seeking approval from an ethics committee – but also of what has been termed ‘ethics in practice’ or ‘ethically important moments’: the everyday ethical issues that arise when conducting research involving humans (Guillemin and Gillam 2004, 263).

In the conduct of this study, ethical issues could have potentially arisen due to two main factors: participants’ vulnerability associated with their socio-economic disadvantage; and the potentially sensitive nature of the issues participants were asked to discuss. Furthermore, it was anticipated that the sample would include Indigenous people, a particularly vulnerable population at multiple disadvantage (SCRGSP 2009).

The appreciation and acknowledgement of these factors guided my approach as a researcher throughout each stage of the study, and the principle of ‘reflexivity’ – the process of critical reflection both on the kind of knowledge produced and how that knowledge is generated (Guillemin and Gillam 2004) – underpinned my ethical conduct. Furthermore, I was guided by the empowering principles suggested when conducting research with vulnerable groups: respect; prevention of harm and maximisation of benefits; affirmation of participants; and giving something back to participants (Massat and Lundy 1997).

## **Informed consent**

Informed consent is a central tenet of the ethical conduct of research, through which the prospective participant comes to an understanding of what the research is about and what participation involves, and, based on that understanding, makes a free decision about whether or not to participate (Guillemin and Gillam 2004). In accordance with the National Statement value of respect, and general requirements for consent (NHMRC 2007), and to ensure that participants made informed

decisions, I obtained written consent from every participant prior to the conduct of the focus groups and interviews. The consent form included sufficient information on the proposed research, including its purpose, methods and potential benefits, and the implications of participation, including any potential risks (see Appendix 1). The consent form was accompanied by an information sheet that contained information on the right of participants to withdraw at any stage; how privacy and confidentiality would be protected; and what the outcomes of the research might be and how they would be disseminated to participants and the wider community (NHMRC 2007) (see Appendix 2). Both the consent form and accompanying information sheet were written in plain English, and were free of jargon.

### **Payment to participants**

Information on payment to participants was also included in the information sheet (see Appendix 2). Participants were paid \$30 to take part in the study in compensation for their time and potential costs incurred, and in appreciation of their contribution to the study. Reimbursement is a common practice in health research in Australia, particularly among government organisations and universities, and for certain groups such as Indigenous people, and general population samples (Fry *et al.* 2005). Compensation for participation is common in qualitative research, and it has been used in research involving people with diabetes, as payments (Caban *et al.* 2008), gift certificates (Nagelkerk, Reick, and Meengs 2006), or the opportunity to remain at the end of a focus group to attend a session with a diabetes educator (Utz *et al.* 2006).

Although some authors voice concerns about paid-for participation – particularly when conducting research with vulnerable populations – stating that even a small payment might coerce participants to take part (Cook and Nunkoosing 2008), research conducted in Australia has shown that motivations for research involvement are multi-dimensional and rarely driven by economic gain alone (Fry and Dwyer 2001). In this study, paying participants was considered as an act of respect, and acknowledged their expertise and wisdom as a critical component of the research (Morse 2005).

## **Privacy and confidentiality**

The protection of participants' privacy and confidentiality is underpinned by the value of respect (NHMRC 2007). In order to protect participants' privacy, focus groups were conducted in a venue which provided a safe environment, and most interviews were conducted in the participant's home.

All identified data were available to me and my supervisors only. Once the focus groups and interviews were transcribed, I de-identified all the data, and used pseudonyms for identification purposes (Nagelkerk, Reick, and Meengs 2006). In order to protect participants' confidentiality, I excluded any information which could lead to the identification of participants from interview transcripts (Hewitt 2007); in addition, I securely stored all data pertaining to the study during and upon completion of the study: electronic files were password-protected, and hard copies of transcripts and documents containing participants' personal information were securely stored in a locked filing cabinet.

I sought participants' verbal consent prior to audio-recording the focus groups and interviews. In accordance with the principle of reflexivity underpinning my conduct (Guillemin and Gillam 2004), I had anticipated that participants might feel intimidated by the recorder, and that the device might become a barrier between us. Thus, I engaged in small talk as I set up the recorder, trying to build rapport with participants and put them at ease. I found that the presence of the recorder often acted as an ice-breaker, as a number of participants made appreciative comments about its small size, enquired about its performance, and even expressed their interest in owning one. Ultimately, the recorder proved relatively unobtrusive due to its small size and its reliability, and allowed me to fully concentrate my attention on my interaction with participants.

I downloaded the digital audio files on to my password-protected computer as soon as possible after each session, and deleted them from the digital recorder once I had ascertained the integrity of the downloaded files. As I shared the device with other researchers, I paid particular attention to the deletion of the digital files from the recorder, in order to preserve the privacy and confidentiality of the data.

### **Potential harm or discomfort to participants**

According to the principle of beneficence upheld by the National Statement, any potential risk of harm or discomfort to participants should be minimised, and the likely benefit to participants should justify any risks. Furthermore, it is the responsibility of the researcher to ensure the welfare of the participants in the research context (NHMRC 2007).

It was not anticipated that there would be any risk of harm to participants in the study, and I strived to employ empowering techniques such as the use of supportive language and affirmation of participants' experiences to minimise their emotional vulnerability (Massat and Lundy 1997). However, there existed the possibility that participants might experience some degree of emotional or psychological discomfort during the conduct of the interviews as they discussed their experience of disease. In anticipation of this possibility, throughout the data collection period I carried a folder with information on resources available – including counselling services and support groups – which I could make available to any participant showing any sign of distress or discomfort.

As the ultimate goal of the study was to contribute to achieving better health outcomes and a better quality of life for disadvantaged persons living with T2D, any potential discomfort experienced by participants was outweighed by the potential benefit to the wider community and to participants themselves.

### **Potential harm to the researcher**

As a researcher, I placed myself at risk of potential harm by conducting most of the interviews at private homes. This risk was minimised by the implementation of a safety procedure which involved the following steps: advising my supervisors about the interview schedule, including the address and time of the interview, and the name of the person being interviewed; conducting a personal safety assessment of the premises on arrival; and carrying a mobile phone with two emergency contact numbers on speed-dial (my principal supervisor's and my husband's).

## **Aboriginal and Torres Strait Islander Peoples**

In addition to the ethical principles highlighted in this section, the study was informed by the values of reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity, as stated in the *Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003b, 2007).

The ethical considerations surrounding Indigenous participation in the study resulted in modifications to the original data collection methods, including the strategies implemented to recruit participants to the study, and the processes followed for the focus group and interview sessions. These issues are discussed in detail later in this chapter.

### **Participants' perception of me as a researcher**

In accordance with the principle of reflexivity (Guillemin and Gillam 2004) which guided my conduct, I was aware that participants' perception of me could affect the way in which they related to me and, thus, influence their responses. Although it has been pointed out that in research interviews with vulnerable people 'the notion of equality is a myth and an illusion' (Cook and Nunkoosing 2008, 419), I tried to minimise the power imbalance between interviewer and interviewee through the way I conducted and presented myself.

Given participants' position of socio-economic disadvantage, I considered the way I presented myself to participants, paying attention to my appearance and the language I used: I tried to convey a professional yet relaxed and approachable image; and I also tried to put participants at ease by speaking plain English, and adapting my language to participants' level of literacy. A personal characteristic may have influenced participants' perception of me: although I speak fluent English, my European accent identifies me as overseas-born, and I cannot discount the possibility that this characteristic may have contributed to widen the 'distance' between the researcher and those researched' (Mays and Pope 2000, 51). However, as the data collection unfolded, I observed that my accent prompted many participants to enquire about my country of origin and sparked conversation, thus contributing to building rapport.



## ***Qualitative methodology***

A qualitative methodology was adopted for the study, as it was congruent with the theoretical underpinnings of the study (Fossey *et al.* 2002), provided the best fit for the research questions (Oakley 2004), and was consistent with research exploring lay experiences of disease. The study was mainly interpretive, as it focused primarily on the accounts and understandings of participants' experiences and actions; however, in so far as it explored the social and cultural contexts of participants' meanings, it also drew from elements of the critical paradigm (Fossey *et al.* 2002). Furthermore, as the overall aim of the study was to explore the impact of socio-economic disadvantage on the management of diabetes, and the study was underpinned by a SDH framework around the existence of inequalities in health, the research design drew from conceptual tools from conflict theories (Willis *et al.* 2007).

Qualitative research 'attempts to capture people's meanings, definitions and descriptions of events' (Minichiello, Aroni, and Hays 2008, 8), and it differs from quantitative research not only methodologically – in the way the data is handled – but also conceptually – in the nature of the phenomena studied. Qualitative research seeks to understand human behaviour from the participant's perspective, and it is conceptually based on an assumption of reality that is dynamic and negotiated (Minichiello, Aroni, and Hays 2008). Furthermore, in qualitative research participants' voices are privileged, and the nature of researcher-researched interactions are integral to the research process (Fossey *et al.* 2002). Thus, the implications of adopting a qualitative methodology reach beyond the selection of a set of specific research tools. From a paradigmatic perspective, qualitative research reflects an underlying philosophy of science, which distances itself from traditional positivist beliefs and reflects a constructivist position, in which 'reality is best understood by studying the ways in which people perceive, experience, and make sense of, the events in their lives' (Banyard and Miller 1998, 487).

In the past, health research was dominated by epidemiology and the quantitative paradigm, and qualitative methods were seen to have little place in public health. However, the 'so-called qualitative-quantitative divide' (Pope and Mays 2006, 5) has become a moot question, as it is now recognised that qualitative inquiry has made an important contribution to the understanding of health and illness over the last

decades (Morse 2007). Current understandings are that contributions from both quantitative and qualitative research are required when addressing complex social and health issues (Jack 2006), and that qualitative approaches help our understanding of ‘the complex workings of the social, cultural and institutional systems that are central to our health and wellbeing’ (Carter, Ritchie, and Sainsbury 2009, 110). Furthermore, it has been noted that the rising popularity of qualitative health research has coincided with the new ‘primacy of the practical’ (Heron 1996, 42) and the emergence of evidence-based practice (Sandelowski 2004), as qualitative research provides context-sensitive research evidence that contributes to the evidence-based management of the health system and policy-making (Lomas *et al.* 2005; Daly 2009). In its final report to WHO, the CSDH emphasizes the importance of qualitative data in understanding the SDH, stating that quantitative measures are ‘essential to describe the extent of a public health problem but do little to explain the experience of that problem or its impact on people’s lives’ (CSDH 2008, 187).

### **Study design**

The study adopted a cyclical, two-stage design, commencing with focus groups (Stage 1), followed by in-depth interviews (Stage 2). Focus groups and open-ended interviews provide a vehicle for participants to tell their story in their own words, and can become a tool not only for gathering information, but also for individual and group empowerment, and for action and social change (Banyard and Miller 1998).

The study was naturalistic in approach and adopted an iterative design, involving simultaneous data collection and analysis, and iteration between data and social theory (Willis *et al.* 2007). As illustrated in Figure 4.1, the overall study design was informed by social theory and a review of the relevant literature, including the conceptual framework by Brown and colleagues (2004). The theoretical underpinnings of the study informed the sampling process (step 1), and the iteration of data collection and analysis (steps 2 and 3); sampling was conducted until data saturation (step 4); and, ultimately, a theoretical explanation of the experience of disadvantaged persons living with T2D was provided (step 5).

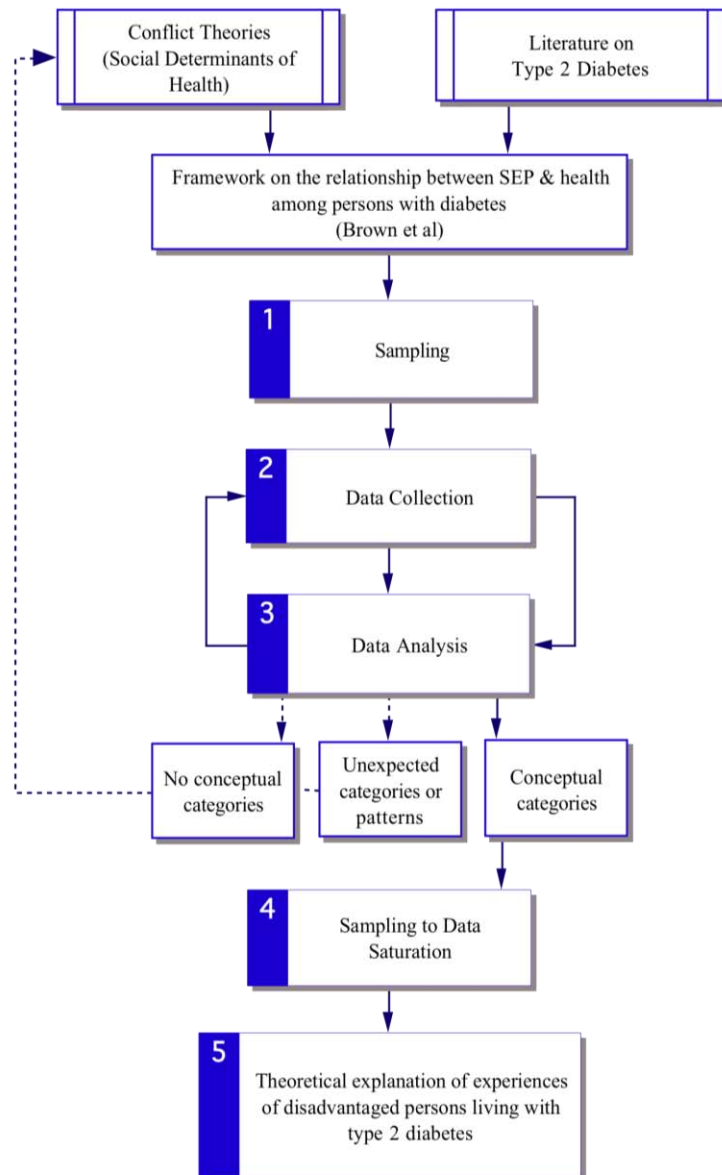


Figure 4.1: Connection between social theory and study design. Source: Adapted from Willis and colleagues (2007).

A consultative approach informed the overall study design, and initial exploratory meetings were held with relevant stakeholders, helping to establish and build respect and trust (Bond Sutton *et al.* 2003). I conducted the study in consultation and collaboration with: Diabetes WA, a state-wide member-based organisation providing support to people with, affected by and at risk of diabetes (2008); Derbarl Yerrigan Health Service Inc (Derbarl Yerrigan), an Aboriginal community-controlled organisation delivering health services across the Perth metropolitan area (2009); the Diabetes Consumer Reference Group (WA) (DCRG), a state-wide consumer group participating in planning, policy development, and the review of services provided to

people affected by diabetes in WA<sup>4</sup> (2006); and staff at the Western Australia Department of Health (WADoH).

## **Study sample**

In this section, I provide a justification for the selection of the main sampling area, and I discuss the selection criteria adopted and the recruitment strategies implemented to achieve the desired sample size. I conclude with a description of the size and characteristics of the final sample.

### ***The main sampling area***

As the study aimed to explore the impact of socio-economic disadvantage on the experience of T2D, and was interested in identifying specific groups of people living in circumstances relevant to the social phenomenon studied, I adopted a systematic non-probabilistic sampling strategy (Mays and Pope 1995). Thus, I selected the suburbs with the highest index of socio-economic disadvantage in the metropolitan area of Perth as the main sampling area, as they were more likely to yield information-rich and illuminative data (Patton 2002).

I identified the area with the highest level of socio-economic disadvantage in Perth through the Socioeconomic Indexes for Areas (SEIFA). SEIFA is a set of four indices used by the ABS to measure socio-economic disadvantage, and includes: the Index of Relative Socio-economic Disadvantage (IRSD); the Index of Relative Socio-economic Advantage and Disadvantage; the Index of Education and Occupation; and the Index of Economic Resources (ABS 2008d). The IRSD has a focus on relative disadvantage, and includes variables of income, education, employment, occupation, housing and other socio-economic indicators such as Indigenous status, disability or car ownership (see Appendix 3) (ABS 2008d).

According to the IRSD by postcode for 2006, the postcode WA 6061 ranked 19 on the list of 327 Western Australian postcodes, and was the most disadvantaged in the Perth metropolitan area (ABS 2006c). Thus, I selected the suburbs covered by the postcode WA 6061 – Balga, Mirrabooka, Nollamara and Westminster – as the main

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<sup>4</sup> As of January 2011, DCRG was no longer in operation.

sampling area for the study (a description of the main sampling area is presented in Chapter 5).

### ***Selection criteria***

The study design originally incorporated three inclusion criteria and one exclusion criterion. However, in accordance with the principles of emergent design flexibility and attentiveness to situation dynamics informing qualitative inquiry (Patton 2002), I made several adjustments during the data collection period, which were congruent with the overall research methodology.

#### **Inclusion criteria**

##### ***Aged 18 years or over***

Participants had to be aged 18 years or over to take part in the study. Despite the accumulating evidence on its increasing prevalence among children and adolescents (Alberti *et al.* 2004), T2D is most commonly diagnosed among adults (AIHW 2008b), and, thus, it was unlikely that any potential study participant would be younger than 18 years of age. However, explicitly excluding minors from taking part in the study minimised any ethical issues relating to participants' capacity to consent. Furthermore, this inclusion criteria is consistent with qualitative research on lay experiences of diabetes conducted in Australia (Kokanovic and Manderson 2006; Lee 2007) and overseas (Zoffmann, Harder, and Kirkevold 2008).

##### ***Diagnosed with type 2 diabetes for at least one year***

In order to be included in the study, participants had to have been diagnosed with T2D for at least one year. Diagnosis of T2D was interpreted as a person having been told by a health professional that they had 'diabetes' or 'sugar diabetes' (as some participants referred to their condition). One participant who had been diagnosed with hyperglycaemia for approximately one year was recruited to the study. The rationale for this inclusion was that intermediate hyperglycaemia – impaired glucose tolerance (IGT) or impaired fasting glucose (IFG) – can be a precursor to diabetes (WHO and IDF 2006), and, in addition, the participant had been prescribed medication typically prescribed to diabetes patients and was experiencing common self-management issues associated with a diagnosis of diabetes.

As the study explored the experience of living with T2D, setting a minimum period of one year since diagnosis meant that participants were more likely to have a better understanding and a greater insight into the impact of the disease on their daily lives. This time frame is consistent with other qualitative studies on the lay experience of diabetes conducted in Europe (Parry *et al.* 2004; Zoffmann, Harder, and Kirkevold 2008), and the US (Savoca, Miller, and Quandt 2004). In accordance with the principle of flexibility (Patton 2002), the minimum period of one year was interpreted loosely, and participants who had been diagnosed for 10 or 11 months were still recruited to the study. However, one potential participant who had just been diagnosed was considered ineligible as they were still coming to terms with their diagnosis and were unlikely to have insight into the impact of diabetes on their lives.

### *Living in the sampling area*

It was originally intended that all participants to the study would be recruited from the suburbs of Balga, Mirrabooka, Nollamara and Westminster. However, as recruitment of participants to the study unfolded, the decision was made to include participants living in other metropolitan suburbs. The study was interested in exploring the impact of socio-economic disadvantage on the experience of T2D, and the focus was on individual-level, rather than area-level disadvantage. Selecting the suburbs with the highest index of socio-economic disadvantage as the sampling area was likely to yield participants who were at disadvantage, but did not guarantee it. Thus, a person could live in the sampling area but not be disadvantaged, and, conversely, a person might live outside of the sampling area and yet meet criteria of socio-economic disadvantage based on measures of income, education and occupation.

This issue arose at the onset of the data collection process, as recruitment to the Indigenous focus group session unfolded. The Indigenous sample for the study was mainly drawn from clients attending the Derbarl Yerrigan's Mirrabooka clinic, and as its catchment area extended to neighbouring suburbs in the north metropolitan area, it was decided to include participants regardless of their suburb of residence. The rationale for this inclusion was that in the Australian context, Indigenous status alone is considered an indicator of socio-economic disadvantage (ABS 2008d), and, in addition, having a large Indigenous sample in the study would reflect the

significantly higher prevalence of diabetes among Indigenous people in Australia (AIHW 2008b). As a result of this amendment to the original selection criteria, of the total number of Indigenous participants recruited to the study (n=18), the majority (n=13) lived in neighbouring suburbs, while the remainder (n=5) lived in the main sampling area.

Consistent with the approach adopted for the recruitment of the Indigenous sample, non-Indigenous people living outside the main sampling area who expressed an interest in participating were also recruited to the study. However, as most recruitment strategies implemented to recruit non-Indigenous participants to the study targeted the main sampling area only, out of the total number of non-Indigenous participants (n=20), the majority (n=17) lived in the main sampling area, while only three lived in neighbouring suburbs.

### **Exclusion criteria**

#### *No participation in both stages*

It was originally intended that participants in Stage 1 of data collection (focus groups) would not be eligible to take part in Stage 2 (in-depth interviews). However, in accordance with the principles of flexibility and attentiveness to situation dynamics (Patton 2002), I decided to interview two Indigenous participants who had taken part in the focus group, as they were present at the time of the interview sessions at Derbarl Yerrigan and were mistakenly expecting to be interviewed.

#### *No socio-economic disadvantage*

Finally, not meeting the criteria for socio-economic disadvantage became a *de facto* exclusion criterion. Thus, a total of five interview participants were excluded from the final data analysis, as their socio-demographic profile – based on measures of income, education and occupation – did not match that of the rest of the sample. Of the total of five participants excluded, only one lived in the main sampling area, while three lived in neighbouring suburbs and one lived in a south metropolitan suburb.

## ***Recruitment of participants***

As the study sample was drawn from vulnerable, ‘hard-to-reach’ populations, I adopted a collaborative approach and implemented a range of strategies to achieve the desired sample size. Non-Indigenous participants were recruited with the support of WADoH’s Mirrabooka Community Health Centre and community-based diabetes support groups, while Indigenous participants were recruited in collaboration with the Aboriginal Health Team at Diabetes WA, Derbarl Yerrigan, and the Aboriginal Health Team at WADoH’s Mirrabooka Community Health Centre.

A range of promotion and recruitment strategies was required to achieve the desired minimum number of participants in both stages of data collection. With regard to the focus groups, in September 2008 I circulated promotion and recruitment materials (see Appendix 4) to all relevant stakeholders, including: coordinators of the two diabetes support groups whose catchment area covered the sampling area; diabetes clinics at all hospitals providing services to patients living in the sampling area; key personnel at WADoH; Diabetes WA; DCRG; and the Health Consumers’ Council WA (HCC)<sup>5</sup>. However, this approach did not yield the desired minimum number of participants, and I had to implement additional strategies, including: displaying flyers at community health centres, recreational facilities, library, local chemists and local supermarkets; and doing a mail-box drop in selected streets in the four suburbs included in the sampling area. Although time-consuming, these strategies proved effective. In addition, a culturally-appropriate flyer was specifically developed in collaboration with Diabetes WA’s Aboriginal Health Team Coordinator to promote the Indigenous focus group (see Appendix 5).

With regard to the interviews, participants were recruited to the study through two main recruitment drives, the first commencing in March 2009, and the second in August 2009. During the first round, participants were recruited through a range of strategies including: electronic and mail circulation of recruitment flyers (see Appendix 6); and placing advertisements in the community newspaper covering the main sampling area (see Appendix 7), the HCC quarterly newsletter, and Diabetes WA’s magazine (see Appendix 8). In addition, a snowballing technique resulted in the recruitment of additional participants. During the second round, participants were

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<sup>5</sup> Peak health consumer organisation in Western Australia.



largely recruited through an advertisement in the same community newspaper, as this was the most effective recruitment method during the first round. Consistent with the cyclical nature of the study, and the continuous iteration between data and social theory (Willis *et al.* 2007), this second recruitment drive was open to any eligible participants, but primarily targeted those aged 55 or younger (see Appendix 7).

Most potential participants self-identified and contacted me directly to express their interest in being part of the study. Once I had ascertained their eligibility, I mailed participants a letter confirming the date, time and venue for the session, and containing a copy of the information sheet (see Appendix 2), and consent form (see Appendix 1). Following the sessions, I sent participants a thank-you letter acknowledging their contribution to the study (see Appendix 9), and offering the possibility of receiving a copy of the transcript of their interview. Finally, in accordance with the principle of giving something back to participants (Massat and Lundy 1997), I mailed participants a lay summary of results in November 2010 (see Appendix 10).

The recruitment procedure followed for the Indigenous sample varied from that followed for the rest of the sample. Although eligible participants were originally requested to contact Diabetes WA's Aboriginal Health Team Coordinator to register their interest in taking part in the focus group (see Appendix 5), this did not happen. Instead, a Derbarl Yerrigan worker recruited eligible participants for the focus group and interviews among her clients and liaised with me directly.

## **Sample**

A total of 43 participants took part in the study. As discussed earlier, five interview participants were excluded from the final analysis, as their socio-demographic characteristics did not fit the profile of the rest of the sample; these exclusions brought the final sample size to 38 participants. As the study sought an in-depth understanding of participants' experience of disease, and was concerned with exploring details, contexts and nuances, 'depth' was prioritised over 'breadth' (Patton 2002). The sample size achieved was consistent with other qualitative studies on lay experiences of diabetes (Dovey-Pearce, Doherty, and May 2007; Gask, Ludman, and Schaefer 2006; Loos and Kelly 2006; Mayer and Rosenfeld 2006; Parry *et al.* 2004), and met the criteria of appropriateness and adequacy (Fossey *et al.*

2002), allowing for data saturation and the formulation of a theoretical explanation to occur (Mays and Pope 1995). The sample was large enough to reflect the diversity in terms of disadvantage within the population targeted, while being restricted for 'richness', and for feasibility considerations.

Socio-demographic information on study participants included in the data analysis (n=38) is provided in Table 4.1. Overall, the age distribution was consistent with the general distribution of disease of diabetes (AIHW 2008b). With regard to sex, male participants were not as well represented as females (n=10 and n=28 respectively), which does not reflect the higher prevalence of diabetes among males in Australia (AIHW 2008b). In this study, the skewed sex representation was due to the disproportionate number of Indigenous female participants. While in the non-Indigenous subsample (n=20), the representation of males and females was almost equal (n=9 and n=11 respectively), among the Indigenous subsample (n=18) only one participant was male.

The majority of participants (n=29) were born in Australia, while the rest of the sample (n=9) were born overseas. Among those born overseas, there was a subsample of participants from Indian background (n=4), three of them born in India and one in Myanmar (formerly Burma). The high number of Australian-born participants is a reflection of the large Indigenous subsample; when considering the non-Indigenous subsample alone (n=20), the representation from Australian- and overseas-born participants was almost equal (n=11 and n=9 respectively), which is consistent with the socio-demographic profile of the main sampling area (see Chapter 5).

With regard to household composition, the sample had an almost equal representation of participants with and without partner (n=19 and n=18 respectively), and included a subsample formed by four married couples. The majority of participants (n=27) reported not having dependent children living at home.

Table 4.1: Selected socio-demographic data on study participants (n=38).

Characteristic		No of participants
<b>Age (years)*</b>	25-34	1
	35-44	1
	45-54	7
	55-64	9
	65-74	12
	75+	7
<b>Sex</b>	Female	28
	Male	10
<b>Indigenous status</b>	Indigenous	18
	Non-Indigenous	20
<b>Country of birth</b>	Australia	29
	Other†	9
<b>Partner/spouse*</b>	Yes	19
	No	18
<b>Dependent children living at home</b>	Yes	11
	No	27
<b>Education*</b>	Year 8	7
	Year 9	4
	Year 10	8
	Year 11	2
	Year 12	5
	TAFE <sup>^</sup>	7
	Bachelor Degree	2
<b>Weekly household income*</b>	\$1-\$199	12
	\$200-\$399	12
	\$400-\$599	7
	\$600-\$799	4

\* Data not available for all participants; † Burma (n=1), India (n=3), Slovenia (n=1), The Netherlands (n=1); UK (n=2); US (n=1); <sup>^</sup> Technical And Further Education.

The levels of educational attainment reported by participants varied, but were generally low. Out of the total 35 participants who provided information on their education, the majority (n=21) reported having completed Year 11 or lower, and included seven participants who reported having completed Year 8 only. Among the rest of the sample (n=14), five reported having completed Year 12<sup>6</sup>, seven reported having obtained a technical qualification and two reported having completed a university degree.

Income levels reported by participants were very low. Out of the total 35 participants for whom information on income was available, the majority (n=24) reported that

<sup>6</sup> Last year of secondary education.

their weekly household income was in the two lowest income brackets, which is consistent with most participants' reports of their source of income: age or disability pensions, or unemployment benefits.

With regard to participants' occupation (not included in Table 4.2), only one participant reported being employed at the time of the interview. The occupation most commonly reported was described as 'home duties' or 'housewife' (n=12); while the rest of participants described their status either as retired (n=8), in receipt of a disability pension (n=5) or unemployed (n=2).

Table 4.2 provides an overview of diabetes-related information on study participants for whom data was available (n=35). The majority of participants (n=23) reported having been diagnosed for 10 years or less, and only two reported having had diabetes for more than 20 years. The issue of the validity of the data relating to the time of diagnosis needs to be considered, as some participants could not recall the time of their diagnosis and provided an approximate estimation.

Table 4.2: Diabetes-related information on study participants (n=35).

<b>Characteristic</b>	<b>No of participants</b>	
<b>Diagnosis (years)</b>	1-5	11
	6-10	12
	11-15	3
	16-20	7
	21+	2
<b>Diabetes management regimen</b>	Insulin only	3
	Insulin & diabetes medication	8
	1 diabetes medication	11
	2+ diabetes medications	11
	No diabetes medication	2
<b>Oral hypoglycaemic agents*</b>	Avandia	3
	Diamicron	11
	Glucobay	0
	Metformin	28
	Novonorm	1
	Other	3
<b>Medication for other conditions</b>	Yes	30
	No	5

\* Multiple responses possible.

With regard to diabetes management regimen, the majority of participants (n=22) reported being on oral hypoglycaemic agents, while 11 reported being on insulin;

only two participants reported not being on any diabetes medication. Significantly, most participants (n=30) reported being on medication for other health conditions. This is consistent with data on the prevalence of diabetes co-morbidities, and also reflects the practice of prescribing diabetes medication alongside medication to control hypertension and hypercholesterolemia (Diabetes Australia 2010). Among other diagnosed health problems (not included in Table 4.3), the most commonly reported were hypertension (n=22), hypercholesterolemia (n=16), cardiovascular disease (n=6) and asthma (n=5), while arthritis, lymphoedema and cancer were also reported, and one participant reported being on dialysis due to renal failure.

## **Data collection**

In this section, I discuss the data collection process, describing the qualitative methods adopted, and providing a rationale for any amendments to the original methodology design. As discussed earlier in this chapter, the study adopted a cyclical two-stage design: participants' experiences and attitudes were elicited through focus groups held in October 2008 (Stage 1), followed by in-depth interviews held over a period of nine months from March to November 2009 (Stage 2). This timeline allowed for data analysis of each cycle within each stage to occur, and inform subsequent cycles, which was consistent with the iterative nature of the study (Willis *et al.* 2007).

I audio-recorded the focus groups and interviews and took notes during the sessions. Only one interview participant declined to have the session recorded; in this case, I took extensive notes during the interview, including information-rich verbatim quotations. Participants' demographic data and diabetes-related information were collected through a brief questionnaire.

### ***Background questionnaire***

Demographic data and relevant diabetes-related information were obtained from all participants in the study through a one-page background questionnaire. The questionnaire was designed to provide sufficient demographic information to ascertain participants' SES and to provide an overview of their medical history. However, as the questionnaire was originally intended to be self-administered and it

was anticipated that some participants might have low levels of literacy, its design was kept to a simple format, both in layout and content.

The background questionnaire was comprised of two sections (see Appendix 11):

- 1) *About You*. This section covered demographic data and included questions on: age; sex; partner; dependent children; Indigenous status; country of birth; education attainment; occupation; and household income.
- 2) *About Your Diabetes*. This shorter section covered information on participants' diabetes and other medical conditions, and included questions on: length of diagnosis; diabetes medication; other diagnosed medical conditions; and medication taken for any other medical condition.

The questionnaire was originally designed to be self-administered and completed prior to commencing the focus group and interview sessions. Self-administration did occur during the focus group sessions; however, during the interviews I administered the questionnaire myself before the sessions. As the interview cycles unfolded, I found that this method of administration contributed to building an initial rapport with participants, and it was more efficient and less time-consuming. Furthermore, administering the questionnaire myself reduced the burden placed on participants and, thus, the risk of inducing feelings of disempowerment, as during the interview process I observed that some participants had very low levels of literacy.

### ***Stage 1: Focus groups***

During Stage 1 of the study, data were collected through two focus groups held in October 2008. The first session involved Indigenous participants, while the second, conducted one week later, primarily targeted non-Indigenous participants.

The rationale for the selection of this method of data collection was twofold: firstly, in accordance with the cyclical and iterative nature of the study, the analysis of the data gathered through the focus group sessions informed the development of the interview schedule; and secondly, focus groups are a particularly culturally sensitive data collection technique (Kitzinger 2006), which made them an appropriate option given the characteristics of the study sample. Focus groups allow for the bridging of personal experiences and social contexts (Warr 2005), and provide an opportunity for participants who feel safer in a group environment to share their experiences, capitalising on the interpersonal communication between participants to generate data, which might highlight cultural values or group norms (Kitzinger 2006).

## **Development of the focus group schedule**

I developed a focus group schedule based on a review of the literature, ensuring that the key areas relating to the study objectives were addressed. The areas for discussion included in the focus group schedule were the following:

- 1) *Living with and managing your diabetes*, including all aspects of diabetes self-management;
- 2) *The medical care of your diabetes*, including participants' experiences of accessing healthcare services;
- 3) *The challenges of managing your diabetes*, including barriers to effective self-management;
- 4) *The impact of diabetes on your life*, including personal, family, social and financial aspects; and
- 5) *Your priorities for a better quality of life*.

A series of questions or probes were used to trigger debate on issues relating to each of the key areas. However, in accordance with the naturalistic nature of the study, the flexible approach implemented allowed for participants to elicit additional themes (Tabrizi *et al.* 2007). In addition, a final open question invited participants to add any further comments and discuss any issues that had not been addressed during the session (see Appendix 12).

## **Pilot focus group**

I piloted the focus group schedule in collaboration with DCRG prior to commencing data collection. The pilot session was held in early October 2008 and involved three DCRG members – two participants had a diagnosis of T2D, while the third was the parent of a child diagnosed with type 1 diabetes.

The pilot session lasted approximately 90 minutes and included a review of all relevant documents (information sheet, consent form, and background questionnaire). At the commencement of the session, participants were provided with the information sheet and consent form, and were then invited to complete the background questionnaire. Participants in the pilot session were also provided with a copy of the focus group main areas of discussion for their reference. Once the pilot session was completed, a feedback session took place, and participants were invited to provide verbal and written comments and feedback on all aspects of the session.

Feedback obtained during the pilot session resulted in amendments to the schedule, the information sheet and the background questionnaire. Amendments to the focus group schedule included: adding a probe on medications taken for other conditions under *Living with and managing your diabetes*; adding probes on visits to general practitioners, specialists and diabetes educators, and a question on the quality of the information on diabetes self-management under *The medical care of your diabetes*; and rearranging the order of the last two areas for discussion so that the focus group would conclude with a discussion of participants' priorities for a better quality of life, rather than on the impact of diabetes as was originally planned.

Amendments to the information sheet included minor adjustments to the wording of the first paragraph to enhance readability, and the addition of a sentence clarifying that no identifiable data would be included in any report. The format of the background questionnaire was adjusted in response to a suggestion relating to font size, and its content was amended with the addition of *Metformin* to the list of diabetes medications, and a question on medication taken for any other diagnosed health problems.

### **Main focus groups**

The focus groups were held in consecutive weeks in October 2008; the first session involved Indigenous participants and the second was primarily aimed at non-Indigenous participants. The purpose of holding two separate focus groups was not that of allowing a comparison of the experiences of Indigenous and non-Indigenous participants; rather, holding an Indigenous-specific session was considered culturally appropriate, and consistent with the value of respect (NHMRC 2003b, 2007). In accordance with the principles of sensitivity, reflexivity (Guillemin and Gillam 2004), and emergent design flexibility (Patton 2002), different processes were adopted for the two focus group sessions which are discussed separately.

#### *Indigenous focus group*

The first focus group involved six Indigenous participants and was held on October 22, 2008, at Derbarl Yerrigan's Mirrabooka clinic. This venue was chosen because it is the main Aboriginal health service in the sampling area, and acts as a hub for the



provision of health care and Home and Community Care (HACC) services<sup>7</sup> to Indigenous clients. The session was held on a Wednesday morning to maximise the number of participants, as Wednesdays are clinic days at the nearby WADoH's Community Health Centre, which are attended by many Derbarl Yerrigan clients.

The session was jointly facilitated by two female Aboriginal Health Workers (AHWs) from Diabetes WA; also present were the Derbarl Yerrigan worker who had helped recruit the sample and an AHW from WADoH. One of the Diabetes WA workers acted as the lead facilitator, while the other summarised participants' main points on butcher's paper allowing the group to review and add comments before moving on to another question. I acted as an observer and took notes during the session, and I had the opportunity to ask questions when invited by the facilitators.

The session lasted for approximately two hours, and was followed by lunch, which provided an opportunity for yarning<sup>8</sup> and interacting with participants. Although I originally intended to formalise participants' payment before the session so that they felt free to leave at any time, this did not happen for logistical reasons. Thus, participants received their compensation during lunch, which proved to be more appropriate, as I had time to interact with participants in a relaxed environment and thank them for the contribution.

While meeting criteria of cultural appropriateness, the distinct process adopted for the Indigenous focus group had methodological limitations which are acknowledged. Although I briefed the facilitators several days before the session, during the focus group I observed that at times their approach was that of educators rather than facilitators – thus, for example, I noticed the use of leading questions relating to the benefits of traditional 'bush foods' compared with a Western diet. Also, it cannot be discounted that the presence of the Derbarl Yerrigan and WADoH staff might have influenced participants' responses, particularly those relating to their views on the quality of their care. In hindsight, these issues could have been minimised by conducting a training session and piloting the focus group with the Indigenous facilitators.

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<sup>7</sup> Government-funded services providing support to people living at home and whose capacity for independent living is at risk.

<sup>8</sup> Culturally-appropriate form of conversation.

### *Non-Indigenous focus group*

The second focus group involved four participants and was held on October 28, 2008, at Sadbury Community House, a community centre located in Mirrabooka. Although the session was mainly aimed at non-Indigenous participants, the diverse recruitment strategies implemented yielded one Aboriginal participant.

I facilitated the focus group – which lasted approximately one hour – while a fellow researcher took notes during the session. Prior to the commencement of the session, I collected the consent forms and formalised participants' payments so that they could feel free to leave at any time. I conducted the session following the schedule, using probes when necessary, but allowing the session to flow naturally.

In accordance with the naturalistic design and the principle of flexibility informing the study (Patton 2002), the focus group process was adapted to accommodate participants' needs. As I had been advised by one participant that she would be bringing her young child, I made arrangements with the venue so that toys were available in the room. The presence of the child did not significantly impact the conduct of the session; however, it proved to be somewhat distracting towards the end, as she became restless and sought her mother's attention.

### **Stage 2: In-depth interviews**

Stage 2 of the data collection process involved a series of in-depth semi-structured interviews. As interviews aim to gain access to participants' 'experiences, feelings and social worlds' (Fossey *et al.* 2002, 727), and discover their own meanings (Britten 2006), they have been commonly used to explore lay experiences of chronic disease (Gregory 2005; Rozario and Derienzis 2009), including the experience of diabetes (Parry *et al.* 2006; Savoca, Miller, and Quandt 2004; Manderson and Kokanovic 2009). Furthermore, interviews provide a vehicle for participants 'to tell their story in their own words', and can thus become a tool for empowerment (Banyard and Miller 1998, 495).

### **Development of the interview schedule**

The themes elicited during Stage 1 of the study informed the development of the schedule adopted for the face-to-face interviews in Stage 2, which is consistent with a sequential, combined method approach (Minichiello, Aroni, and Hays 2008). A

semi-structured interview format was adopted to capitalise on the richness of participants' responses, while ensuring a complete understanding of the topic (Inglis, Ball, and Crawford 2005). Consistent with the semi-structured approach, the interview schedule included a series of open questions designed to trigger the conversation, providing a framework within which participants could express their understandings and experiences in their own terms (Patton 2002). The open questions were a blueprint to guide the interview, but the semi-structured approach was flexible enough to allow for the introduction of new themes. In addition, a series of prompts aimed at exploring specific aspects within each of the areas of discussion, ensuring that the key issues were discussed at each interview.

The interview schedule covered four broad areas (see Appendix 13), and the flow of questions was designed to make participants feel comfortable and safe, starting with descriptive questions which could be answered more easily, and then progressing to 'feeling' and 'opinion' questions (Britten 2006). The interview began with a descriptive question asking participants to describe their daily self-management routine: *Could you describe to me what you have to do on a daily basis to control your diabetes?*. The second broad area discussed with participants related to their medical care and started with an open question: *Tell me about the medical care you receive for your diabetes*, and also included an opinion question on participants' view on the quality of their medical care: *I would like to ask you what you think about the quality of care you receive for your diabetes*. A third area explored the impact of diabetes on participants' lives, starting with a descriptive question: *How would you describe what living with diabetes is like to somebody who doesn't know anything about it?*, and following with some opinion and feeling prompts on the impact of diabetes and the existence of support mechanisms. Finally, an opinion question explored participants' views on how to improve the quality of life of people living with diabetes: *When you think about the care you receive for your diabetes, how do you think the health system could make things better for people living with diabetes?*.

### **Pilot interviews**

The interview schedule was piloted twice during February 2009. The first person to pilot the schedule was a male in his late twenties recruited through a colleague. The interview took place at the participant's workplace, and lasted approximately one

hour. I originally intended to conduct one pilot interview only; however, given the participant's nursing background and his familiarity with the research process, I decided to pilot the interview schedule a second time with a person who fitted better the demographic characteristics of the study sample. Thus, a second pilot was held involving a female in her early seventies from a CaLD background recruited through my elderly neighbour. This session was held at the participant's home, in the presence of my neighbour, and lasted approximately eighty minutes.

I recorded both sessions using a digital audio recorder, and I also took some notes during the interviews and wrote extensive notes as soon as practicable after the sessions. The notes included observations and personal reflections on the participant, the environment and the interview, and my personal reaction to the interview process.

The pilot sessions resulted in the minor adjustments to the interview schedule, including: changes to the wording of some questions; improvements to the flow between questions; addition of some prompts; and adjustments to the wording of the questions aimed at eliciting participants' views on how to improve healthcare services.

### **Main interviews**

Twenty-eight interviews were held between March and November 2009. These included seven sessions with two participants and 21 individual sessions, bringing the total number of interviewees to 35. However, as discussed earlier, five individual interviews were excluded from the final data analysis, bringing the total number of interview participants included in the final analysis to 30.

Interview participants included 11 Derbarl Yerrigan clients, and, similar to the focus group sessions, the process followed for these interviews varied significantly from that followed for the rest of the sessions. In the interest of readability, and as the majority of interviews were conducted with participants other than Derbarl Yerrigan clients, I discuss the generic interview process first, and then describe the specific circumstances surrounding the interviews involving Derbarl Yerrigan clients.

I conducted all interviews myself, which prevented inter-interviewer variation (Patton 2002). Also, in recognition of the fact that the setting of interviews affects

their content (Britten 2006), and in accordance with the naturalistic nature of qualitative inquiry (Patton 2002), I conducted the interviews at participants' homes. Participants were offered the possibility of nominating an alternative venue of their choice; however, all participants included in the final data analysis chose to conduct the interviews at home. This naturalistic setting required me to have a flexible and adaptable attitude with regard to the physical environment and surrounding circumstances. Thus, I conducted interviews in gardens, kitchens, lounges and dining rooms; and the sessions were interrupted by telephone calls, visits from neighbours, and the presence of participants' pet animals, including cats, dogs and ferrets. Also, I conducted two interviews in the presence of participants' relatives: on one occasion, a participant's mother and sister were present in the room during the interview but sat reading quietly and did not disrupt the interview; on another occasion, however, at the participant's request I conducted the interview while his wife sat with us, and her presence proved rather disruptive, as she frequently spoke on her husband's behalf and constantly engaged in conversation with her husband and with me.

As discussed elsewhere in this chapter, interview participants included four married couples. Couples were given the option of being interviewed separately or together; two couples opted for a separate interview, while the other two were interviewed together.

As is consistent with a semi-structured approach, the sessions did not have a predetermined duration, although it was anticipated that they would have a maximum duration of 90 minutes. The mean duration of the interviews was 65 minutes; however, a wide range was observed, with the shortest session lasting 37 minutes and the longest two hours.

#### *Interviews with Derbarl Yerrigan clients*

Of the total 13 interview participants who self-identified as Indigenous, 11 were Derbarl Yerrigan clients. The process followed for these interviews was significantly different to that followed for the rest of the interviews, largely due to the fact that the sessions were scheduled by the Derbarl Yerrigan HACC worker who recruited the Indigenous sample, and I was guided by her on the most convenient and culturally appropriate manner in which to conduct the interviews.

All interviews took place during one morning at Derbarl Yerrigan's Mirrabooka clinic. Participants were given the choice of being interviewed in pairs or individually, and most opted for a two-person interview. Given the number of participants and the time restrictions, the duration of the sessions was limited to 20 minutes; thus, I conducted all six sessions consecutively over a period of two hours. Scheduling and strict timing of the sessions by Derbarl Yerrigan's HACC worker were instrumental to ensure that the interviews ran smoothly. I conducted the interviews in a small room, allowing for privacy and confidentiality to be maintained. However, as the door was at times left open, the sessions were somewhat disrupted by background noise from the nearby conference room where the rest of participants were gathered. In addition, due to the busy schedule, as I was wrapping up one session, participants scheduled for the next session would typically be already waiting, either at the door or inside the room, which proved distracting.

The time constraints and the circumstances surrounding the interviews limited the in-depth exploration of some areas included in the interview schedule. As I had not been advised in advance about the time constraints, I had to make a judgement on the spot on what could be achieved within the 20-minute-period and prioritise specific areas. Guided by the values stated in the *Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003b), in particular the value of respect, my main priority was to ensure that participants understood the objectives of the study and made an informed decision as to whether to participate or not. Thus, despite the time constraints, I allocated several minutes to informing participants about the study, answering any questions, and obtaining their written consent once I was satisfied that they were making an informed decision. I strived to obtain as much demographic and diabetes-related information as possible; however, it was not always possible to complete the background questionnaires fully. In some instances, I had to complete the questionnaire during the session with the information provided by participants throughout the interview, and did not always have the opportunity to fill any gaps at the end of the session. I prioritised the discussion of self-management and medical management aspects, as these could be explored with descriptive questions which could be more easily answered (Britten 2006). I then progressed on to opinion questions, and explored participants' perceptions of the quality of their care. Time constraints allowed for a more limited

exploration of the impact of diabetes and of participants' priorities for a more effective management.

## Data analysis

In accordance with the cyclical and iterative nature of the study, data collection and analysis occurred simultaneously, and there was continuous iteration between data and social theory (Willis *et al.* 2007), as illustrated in Figure 4.2:

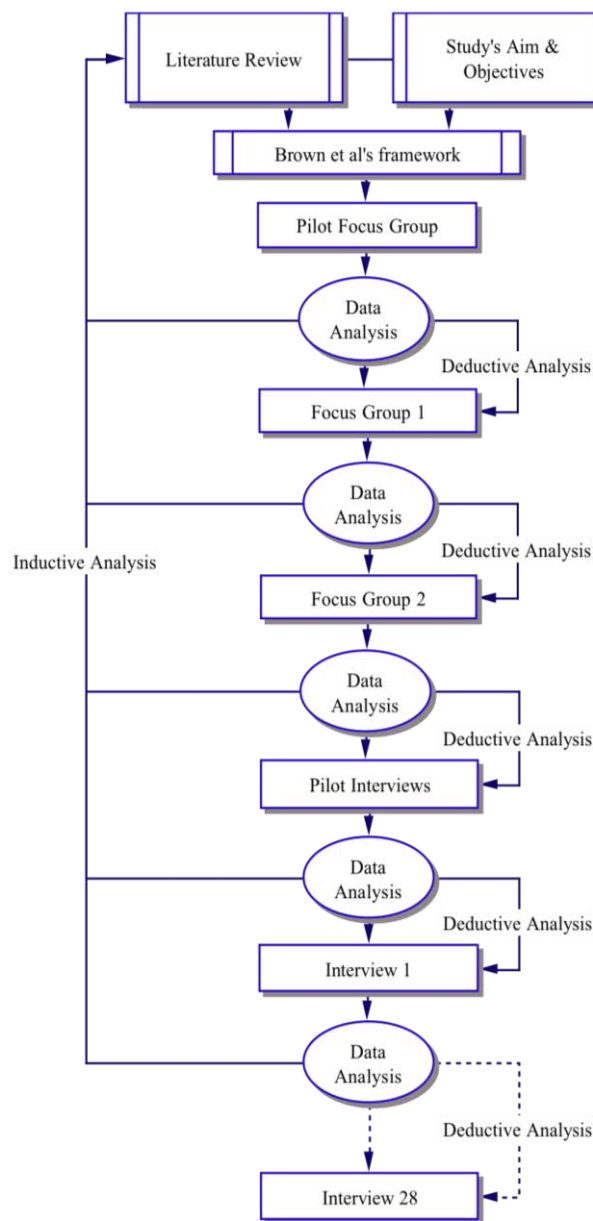


Figure 4.2: Iterative process of data collection and analysis

The analytical process began when data collection commenced, and the data already gathered were analysed and fed into the on-going data collection (Pope, Ziebland, and Mays 2006). Data analysis was influenced by theoretical perspectives and involved a fluid, non-linear movement between the original data and the emerging interpretations (Pope, Ziebland, and Mays 2006). Deductive data analysis aimed to identify conceptual categories derived from the theoretical concepts underpinning the study (Willis *et al.* 2007) – in particular the conceptual framework on the relation between SEP and diabetes health outcomes by Brown and colleagues (2004) (see Chapter 3) – while an inductive approach was adopted to identify new categories.

Data analysis was aided by the use of *NVivo 8*, a software package that helps accessing, managing, shaping and analysing qualitative data (QSR International 2007). As has been pointed out, the software does not perform the analysis (Auld *et al.* 2007), but it enables efficient management of the data required when dealing with a large amount information (Garcia-Horta and Guerra-Ramos 2009). As a novice *NVivo 8* user, I found that learning and using this qualitative data analysis software (QDAS) application from the inception of the study facilitated my immersion in the data. In addition, the use of *NVivo 8* enhanced the validity of the research by adding more rigour to the process and making methodology and analysis more transparent (Siccama and Penna 2008).

Data analysis generally followed the steps described by Green and colleagues: immersion in the data; coding; creating categories; and identification of themes (2007). However, as deductive analysis was based on an existing conceptual framework, coding was performed using already identified categories, resulting in the consolidation of the ‘coding’ and ‘creating categories’ steps.

### ***Immersion in the data***

Immersion in the data commenced with data preparation, as I transcribed verbatim all digital audio files onto a word processor. As qualitative research can produce large amounts of data, and transcribing is a time-consuming task (Pope, Ziebland, and Mays 2006), in consultation with my supervisors I considered hiring a research assistant to transcribe the files; however, I disregarded this option. The benefits I drew from transcribing the files myself far outweighed the time spent on the task, as this process allowed me to fully immerse myself and become ‘intimate’ with the data



from the commencement of the data collection period. I originally intended to transcribe each file immediately after each session; however, this proved impracticable, as the interviews were scheduled almost on a daily basis over a period of several weeks, leaving no time to fully transcribe each file after the session. Thus, transcribing the audio files was an on-going process, and allowed for initial analysis of the data gathered informing subsequent cycles: focus group transcripts were transcribed and analysed before commencement of the interview sessions; and transcription of the first round of interviews was completed prior to the second round of interviews.

I transcribed the audio files verbatim, including stutters, and positive (*uh-huh*) and negative (*nuh-uh*) minimal responses; I also tagged any relevant events taking place during the interview and recorded participants' non-verbal reactions, which helped contextualise their comments. In the transcription of the audio files, I followed this process: first, I completed a draft transcript which provided a firm basis for an initial data analysis; I then reviewed the audio file and transcript to fill any gaps; I reviewed the transcript and audio file a second time to clarify or contextualise participants' comments as needed; finally, when the verbatim transcripts were completed, I imported the resulting electronic files into *NVivo 8*.

Verbatim transcription of the audio files yielded over 400 two-sided pages of single-spaced text. In addition to the focus group and interview transcripts, I incorporated observational notes taken during and immediately after the sessions, my field diary, documentary material, and my notes on the on-going analytical process, allowing for the research process beyond interview transcripts to inform the analysis (Green *et al.* 2007).

### ***Coding the data***

Once I completed the verbatim transcripts, I performed a thematic analysis using coding categories obtained from the framework developed by Brown and colleagues (2004). In so far as the deductive analysis was based on an existing conceptual framework, deductive analysis was akin to a framework approach (Ritchie, Spencer, and O'Connor 2003), and was, thus, more structured and strongly informed by *a priori* reasoning (Pope, Ziebland, and Mays 2006).

I first developed a list of coding categories based on the elements of the conceptual framework by Brown and colleagues (2004); this list was reviewed and categories were refined in consultation with my supervisors, until consensus was reached on a final list of coding categories (see Appendix 14). I then replicated this list of coding categories within *NVivo 8*, as Figure 4.3 illustrates. Coding categories – or ‘tree nodes’ – were created according to two main levels: level 1 tree nodes related to main elements of the framework described by Brown and colleagues, while level 2 nodes related to specific domains within each of the elements described by the authors (2004); level 3 nodes were created when necessary, but were kept to a minimum.

Name	Sources	References
Covariates	0	0
Distal Community	14	55
Environment	1	5
Healthy Food	9	15
Neighbourho	5	19
Places to Exe	5	7
Transport	3	7
Distal Health Care System	14	38
Care Coordin	15	28
Financial Arr	17	47
Organisation	20	80
Self-manage	18	48
Distal Individual	4	17
Communicati	18	56
Cultural Fact	12	31
Mental Healt	5	12
Social Netwo	16	25
Stress	13	87
Subjective Ex	9	25
Health Outcomes	4	4
Proximal Access to Care	10	30
Proximal Health Behaviours	20	65
Clinical Self-	0	0
Lifestyle Fact	8	14
Proximal Process	3	5
Quality of Car	24	166
SES Community	4	8
SES Individual	16	30

Figure 4.3: Codes or ‘tree nodes’ created in *NVivo* (screenshot)

Upon completion of the list of coding categories, I started coding the data. Coding is a detailed, taxonomic process of sorting and tagging data (Green *et al.* 2007). It is the process of applying descriptive labels to segments of transcripts; however, it is more than labelling, as it requires a clear sense of the context in which statements were

made (Green *et al.* 2007). Thus, I coded the transcripts paying attention to the context, and analysed non-verbal cues to reveal the ‘tone and emotive feeling behind the words’ (O’Leary 2005, 259). Furthermore, I used a multiple coding technique, attributing more than one code to a segment of data when necessary.

As discussed earlier in this section, in addition to deductive analysis, I adopted an inductive approach to identify emerging categories. Thus, I reviewed the transcripts periodically to identify any additional category (Lynch 2000; Loos and Kelly 2006), and, as data analysis progressed, I created new categories and refined the definition of existing categories. I found that *NVivo 8* facilitated data analysis by allowing the management of results through reports which helped identify potential gaps in the data gathered. The only data left uncoded related to non-relevant side conversations which took place during the sessions, for example, when a participant showed me photos of his grandchildren or when the interview was interrupted by the unannounced arrival of a neighbour.



Figure 4.4: Use of traditional data analysis methods

Although I originally intended to conduct the entire data analysis process within the *NVivo 8* application, as data collection and analysis unfolded, I found that manual coding of the hard copy of the transcripts – using techniques traditionally adopted in qualitative analysis such as colour-coding, highlighting and tagging, as illustrated in Figure 4.4 – complemented the use of QDAS. Combining both coding methods enhanced the validity of the data in two ways: firstly, alternating manual and software-assisted coding allowed me to check the consistency of my coding, which was also regularly monitored by my supervisors; and secondly, referring to the manual coding and the hard copies of the transcripts allowed me to contextualise the

coded segments, avoiding the QDAS coding pitfall of seeing only ‘bits and pieces’ and not getting ‘a good feel for the individual as a whole’ (Auld *et al.* 2007, 47).

### ***Identification of themes***

Once I completed the coding of the data, the identification of themes could begin. I began by identifying connections between categories and patterns emerging from the categories; linking the categories and patterns with the social theories underpinning the study led to the identification of overall themes and, ultimately, to the formulation of a theoretical explanation (Green *et al.* 2007).

The identification of themes was aided by *NVivo 8* ‘Models’ feature, which I combined with manual notes and pictorial representations of my interpretation of the data. The visualisation of data in the analytical process has been described as the greatest advantage of using QDAS (Garcia-Horta and Guerra-Ramos 2009), and I used this feature to visually represent categories and sources, and explore existing or potential relationships between them. This allowed for greater depth in data interrogation and facilitated the exploration of underlying relationships (Robertson 2008), thus assisting the qualitative theory-building process (Richards 1999). Figure 4.5 illustrates a visual representation of the links between coding categories relating to one of the study objectives: the exploration of the experience of disease (‘living with diabetes’).

Thus, analysing the relationships between categories, and linking the categories to the social theories underpinning the study, I developed a number of themes around four main areas: experiences and attitudes towards self-management; experiences of living with diabetes; experiences of medical management; and priorities for the effective management of diabetes. The overall themes relating to each of these four areas are presented in detail in separate chapters (Chapters 7, 8, 9 and 10 respectively), while the discussion of the theoretical explanation of participants’ experiences is presented in Chapter 11.

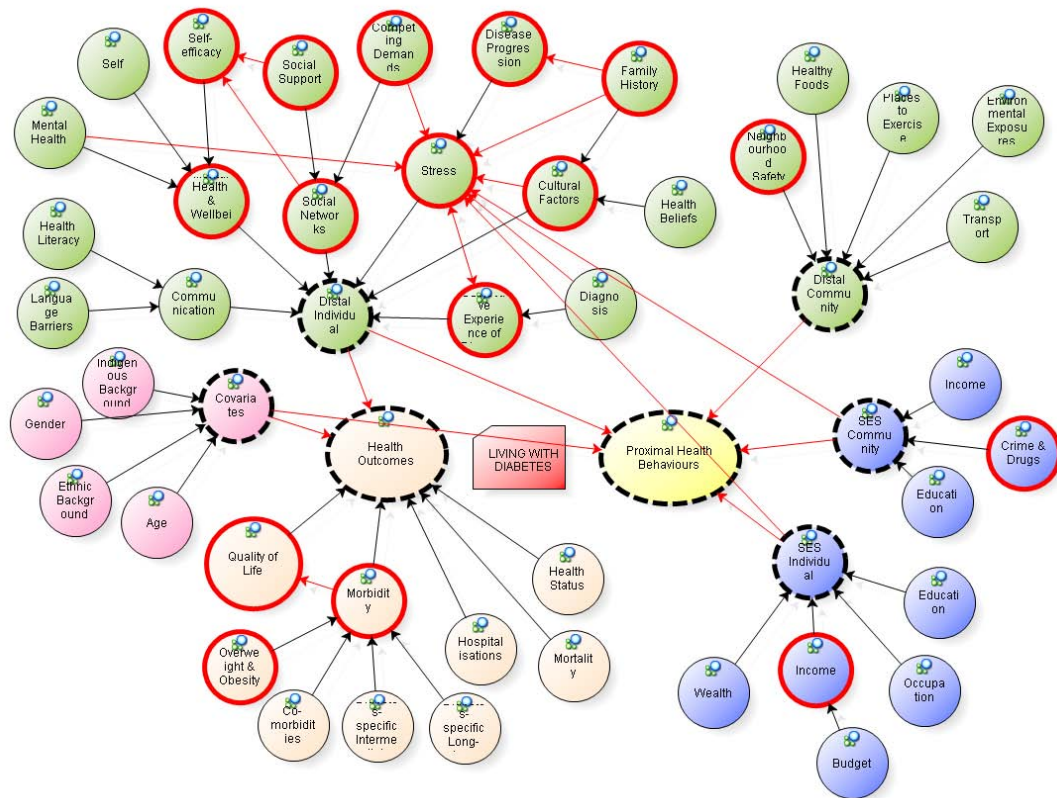


Figure 4.5: NVivo visual representation of links between conceptual categories. Dotted circles: level 1 coding categories; red circles: categories where most of the coding occurred; each colour corresponds to one of the main elements of the framework by Brown and colleagues (2004).

## Limitations of the research design

Limitations in the sampling method are recognised. Given that the focus of the study was on the impact of individual-level socio-economic disadvantage on the experience of disease, the area-level selection criterion relating to the suburb of residence had to be assessed on a one-to-one basis, and value judgments passed to exclude participants from the final analysis. In addition, the possibility of selection bias needs to be recognised, as participants self-selected to take part of the study. Finally, it cannot be discarded that participants might have been motivated by the monetary incentive offered; however, this does not necessarily preclude valid responses.

Time and feasibility constraints limited the study to one metropolitan area in Perth, although the diversity of the sample allowed for the exploration of how the findings might apply to other urban settings. In addition, time and financial considerations prevented the recruitment of participants among the Vietnamese community – the

largest CaLD group in the sampling area. Despite initial consultations with a migrant health worker with links to the Vietnamese community, recruitment efforts had to be abandoned, as it became clear that the recruitment and interview process would require the assistance of a professional interpreter. Thus, the ethnic diversity of the sample does not represent the diversity of the sampling area.

Methodological issues relating to the conduct of the Indigenous focus group and the interviews with Derbarl Yerrigan clients are acknowledged, which limited the in-depth exploration of certain aspects of the study.

Limitations to the validity of the data are also recognised. The data collected through the background questionnaire was self-reported, and its validity relied on participants providing complete and accurate answers. In addition, recall bias cannot be excluded. Furthermore, it cannot be discarded that participants' perception of the power imbalance during the interview encounter, and their perception of me as a researcher might have influenced their responses.

Finally, my own subjectivity also needs to be considered, as the qualitative analysis reflected my own voice and perspective, and, despite my best attempts at being reflexive and self-analytical, my perceptions and biases may have influenced the interpretation of the data.

## **Conclusion**

As discussed in this chapter, the qualitative methodology adopted in this study was underpinned by the study's aim and objectives, and by ethical considerations relating to participants' position of vulnerability. The study adopted a two-stage cyclical design, with focus groups followed by semi-structured interviews. The sample comprised 38 participants (18 Indigenous and 20 non-Indigenous) and was recruited from areas with high indices of socio-economic disadvantage in the Perth metropolitan area. Data were collected from October 2008 to November 2009.

Data analysis was mainly deductive, based on conceptual categories from a framework on the relationship between SEP and health outcomes among persons with T2D (Brown *et al.* 2004), while an inductive approach was adopted to identify new categories. Data analysis was aided by the use of *NVivo 8*, and software-assisted coding was combined with manual coding to enhance the validity of the analysis.

Limitations to the research design are recognised, and related to the sampling method, time and feasibility constraints, methodology, validity of the data, and my own subjectivity in the interpretation of the data.





## Chapter 5 – The Context of the Study

*Healthy people are those who live in healthy homes on a healthy diet, in an environment equally fit for birth, growth, work, healing, and dying.*

*(Ivan Illich)*

### **The place**

The description of the physical and social environment provided in this chapter is based on data from the ABS and the City of Stirling (to which the sampling area belongs), and on my personal observations of the suburbs made during the data collection period.

### ***Physical environment***

The physical environment of a place is comprised of two elements: its geophysical location and the built environment, or ‘the part of the physical environment that is made by people for people’ (Bernard *et al.* 2007, 1844). The geophysical location of an area affects its built environment, and both have an impact on the health and well-being of the people living in it.

### **Geophysical location**

The suburbs of Balga, Mirrabooka, Nollamara and Westminster cover a surface of 16.3 square kilometres (ABS 2008a), and are located in the north metropolitan area of Perth, in the northeast boundary of the City of Stirling (2008a). Figure 5.1 shows the geophysical location of the main sampling area (boundary highlighted in red), approximately eight kilometres from the Perth Central Business District (CBD) (City of Stirling 2008a) and seven kilometres from the coast (Google Map 2010).

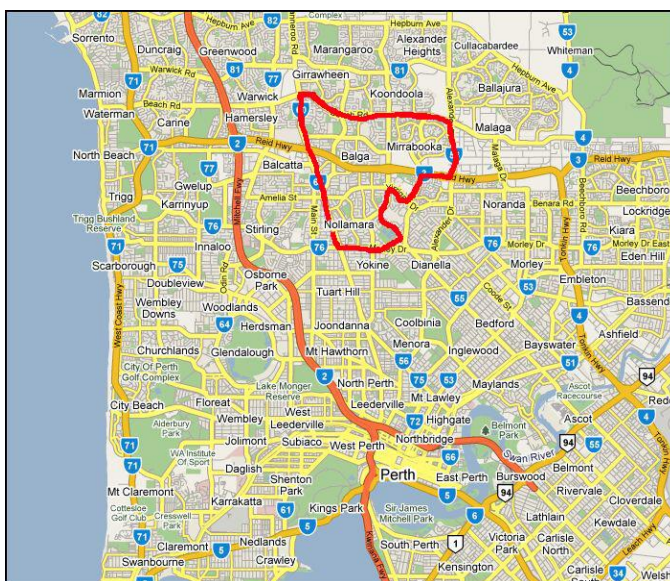


Figure 5.1: Geophysical location of the main sampling area (highlighted). Source: Google Map (2010).

## Built environment

### *Housing*

The main sampling area is an established residential area. According to ABS data, there were 12,115 private dwellings in the sampling area at the time of the *2006 Census of Population and Housing*: separate houses represented 75.4 per cent of the total number of dwellings; semi-detached, row or terrace houses, and townhouses represented 19.7 per cent; and flats, units or apartments only 4.9 per cent, compared with 8.1 per cent in Western Australia (WA) and 14.2 per cent nation-wide (ABS 2007a, 2007b).

The characteristics of the housing stock are influenced by the resumption of land initiated by the State House Commission in the 1950s to form the Mirrabooka Satellite City, a project which was to include the main sampling area and the northern portion of the suburb of Dianella, but was never completed. With the exception of Mirrabooka, which has predominantly low-density housing, and where there still remain a number of vacant blocks, infill development is proceeding apace across all the sampling area (City of Stirling 2010c).

In its 2010 *Local Housing Strategy* document, the City of Stirling highlights that although most of its suburbs are priced above the Perth metropolitan average – reflecting the desirability of coastal and near-city living – the main exception relates to the suburbs of Mirrabooka, Balga and Westminster. The strategy document notes

that this may result in further concentration of affordable housing, exacerbating social inequities (City of Stirling 2010c).

### *Transport*

The sampling area is affected by transport issues that are common to other suburbs in the City of Stirling: a high automobile dependence has created an urban environment which is highly inappropriate for pedestrians, cyclists and public transport users (City of Stirling 2009).

There are bus routes servicing Perth and Mirrabooka, and the transport hub, the Bus Transfer Station, is located in the Mirrabooka Regional Centre (MRC) (City of Stirling 2009), and is currently the object of a \$4.5 million upgrade (City of Stirling 2010b). An *Integrated Transport Strategy* draft document released by the City of Stirling in 2009 identified the following issues affecting the sampling area: the rail system does not cover major employment destinations such as the MRC; the road connections through the MRC need to be improved to increase its functionality; and, in addition, the cycling network does not adequately cover Mirrabooka, and pedestrian connectivity is poor (City of Stirling 2009).

I used public transport for most of the home visits, which allowed me to become well acquainted with the sampling area, and gave me the opportunity to experience the area as a pedestrian. I observed that pedestrian connectivity was poor; often there were footpaths on one side of the street only and they failed to be interconnected, requiring me to cross the street, or walk on the verge or on the road. As I conducted most of the interviews during the late Australian summer, it was still warm, and I found that the low- to medium-density and openness of the built environment, coupled with the absence of trees along the streets, contributed to making the environment unfriendly for pedestrians.

### *Green and open spaces*

The main sampling area is characterised by low- to medium-density housing, and there are a number of green and open spaces dotted around the area. Balga has several parks and recreational reserves, the largest of which is Brian Burke Reserve (City of Stirling 2008b); Mirrabooka is also well provided with public open spaces and parks, the largest being the Mirrabooka Regional Open Space (City of Stirling 2008b); Des Penman Memorial Reserve is the largest reserve in Nollamara (City of

Stirling 2008b); while Westminster has a number of recreational areas (City of Stirling 2008b).

Despite the fact that the sampling area boasts a large number of parks and reserves, during my visits I rarely observed anybody enjoying them. Overall, I observed very little outdoor activity, and with the exception of the areas surrounding the shopping centres, the streets often appeared deserted. This, however, may be due to the fact that many residents would have been at work, as I conducted the interviews during working hours.

### **Social environment**

An overview of the social environment of the sampling area, including its community resources and local amenities, and a brief overview of the crime levels in the area are provided here. The latter is included as some participants raised the issue of neighbourhood safety.

#### **Community resources and local amenities**

At the heart of the sampling area is the MRC, a predominantly commercial and civil centre servicing the City of Stirling's north eastern suburbs (City of Stirling 2002). In 2002, the City of Stirling published the *Mirrabooka Regional Centre Improvement Strategy* working document with the overall aim of revitalising the area and setting specific objectives including: addressing transport issues; coordinating and integrating uses and buildings; diversifying the land uses and services; and improving security, and image and appearance issues (City of Stirling 2002). Figure 5.2 shows Sudbury Place, a street at the heart of the MRC, illustrating the appearance of the area:



Figure 5.2: Sudbury Place, Mirrabooka Regional Centre. Source: City of Stirling (2002).

Currently, the urban design for pedestrians is poor, and access is mainly car-based; in addition, large areas of vacant land and car park detract from amenity (City of Stirling 2009); however, the MRC is currently the object of urban consolidation, and it is envisaged that it will become a mixed-use node, combining commercial and residential uses (City of Stirling 2010c).

Despite the issues affecting the MRC, the Centre is the community resources hub of the sampling area. It is the site of several healthcare services, including a medical centre, a doctor's surgery, a multicultural women's health centre, an Aboriginal community-controlled health service, WADoH's community health centre and mental health service, and a radiology centre. Also located at the MRC are the Centrelink<sup>9</sup> office and several welfare agencies. In addition, the MRC is the site of the public library and the location of the only major shopping precinct in the sampling area, the Mirrabooka Shopping Centre (City of Stirling 2006).

Outside of the MRC, the sampling area has a number of community resources and local amenities, including shopping centres, parks and reserves, and leisure centres (City of Stirling 2006).

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<sup>9</sup> Australian Government statutory agency delivering social security and welfare services and programs.





Figure 5.3: Public open space within the Mirrabooka Regional Centre. Source: City of Stirling (2002).

My regular journeys to the area during the data collection period allowed me to become acquainted with the amenities existing in the suburbs, in particular with those located in the MRC. Although I observed some of the issues affecting the MRC and I experienced its poor pedestrian connectivity, I also observed that the open space between the bus station, the lake and the shopping centre was used both as a transit zone and as a meeting place. I often observed people of African background, and Indigenous people gathering outside the shopping centre, and I also noticed that the small park surrounding the lake illustrated in Figure 5.3 was often frequented by Indigenous people, whom I would typically observe sitting and yarning by the shady trees. My overall impression was that, despite its challenges, the MRC was an integral part of the social fabric of the area, providing community resources and a gathering space.

### **Crime levels**

The sampling area is affected by high crime levels compared with other suburbs in the Perth metropolitan area. According to a report on 2006 crime figures in WA, which ranked crime incidence by quintiles – with suburbs in the first quintile having

the highest level of crime and suburbs in the fifth quintile the lowest levels of crime – Balga and Mirrabooka were ranked in the first quintile in number of offences recorded in the Perth metropolitan area, while Nollamara and Westminster were in the second quintile. However, when crimes figures were analysed per 1,000 population, the overall crime levels in Balga, Mirrabooka and Westminster were ranked in the second quintile, while the level in Nollamara was in the third quintile (Fernandez *et al.* 2008).

Table 5.1 shows the incidence rank for selected offences by suburb in the Perth metropolitan area, with Balga in the first quintile for burglaries, offences against persons and vehicle theft, Mirrabooka for offences against persons and on commercial premises, and Nollamara for burglaries (Fernandez *et al.* 2008).

Table 5.1: Crime incidence rank for selected offences by suburb.

Offence	Balga (incidence rank)	Mirrabooka (incidence rank)	Nollamara (incidence rank)	Westminster (incidence rank)
<b>Burglaries of dwellings</b>	1	2	1	2
<b>Offences against persons</b>	1	1	2	2
<b>Vehicle theft</b>	1	2	2	2
<b>Offences on commercial premises</b>	3	1	3	3

Source: Fernandez and colleagues (2008).

## The people

In this section, I present an overview of the characteristics of the people living in the main sampling area including: data on population and age distribution; Indigenous population; cultural and ethnic background; and socio-economic characteristics.

### ***Population and age distribution***

According to data from the 2006 Census, there were 27,918 persons usually residing in the area covered by the postcode WA 6061 (ABS 2007a). Balga was the suburb with the largest population (8,395 persons), followed by Mirrabooka (7,725), Nollamara (7,439) and Westminster (4,023) (City of Stirling 2010a). Despite being the largest suburb by population, Balga had experienced negative growth between the 2001 and 2006 Census, losing 482 residents (or 5.7% of its total population), while Westminster had lost 36 residents (or 0.9%). In contrast, Mirrabooka had increased its population by 79 residents (or 1.0%) over the same period, while

Nollamara experienced the largest population growth, increasing its population by 554 residents (or 13.8%) (City of Stirling 2010a).

Comparative data on age distribution reveals that the sampling area is home to a young population, with a median age of 33 in WA 6061 compared with 36 state-wide (ABS 2007b) and 37 in Australia (ABS 2007a). The data shown in Table 5.2 are consistent with a comparatively younger population, with age brackets between 0 and 24 years representing larger proportions, and age brackets over 24 years representing smaller proportions of the total population in WA 6061 compared with state and national figures (ABS 2007a, 2007b).

Table 5.2: Population and age distribution: Comparative data for WA 6061, WA and Australia.

Age group	WA 6061	Proportion of Total (%)	WA	Proportion of Total (%)	Australia	Proportion of Total (%)
0-4 years	2,071	7.4	124,812	6.4	1,260,405	6.3
5-14 years	3,985	14.3	271,622	13.9	2,676,807	13.5
15-24 years	4,106	14.7	276,012	14.1	2,704,276	13.6
25-54 years	11,665	41.8	837,776	42.8	8,376,751	42.2
55-64 years	2,708	9.7	213,308	10.9	2,192,675	11.0
65 years+	3,384	12.1	235,556	12.0	2,644,374	13.3

Source: ABS (2007a, 2007b).

### ***Indigenous population***

Another characteristic of the sampling area is its comparatively large proportion of Indigenous residents. According to data from the 2006 Census, Indigenous persons represented 3.5 per cent of the population in WA 6061 (ABS 2007a), compared with 3.0 per cent in WA (ABS 2007b), and 2.3 per cent in Australia (ABS 2007a). The Indigenous population is not uniformly distributed in the area: Balga is the suburb with the highest proportion of Indigenous residents, with 4.4 per cent of its total population, followed by Westminster with 3.9 per cent, Mirrabooka with 3.5 per cent, and Nollamara with 2.2 per cent (City of Stirling 2010a). However, in the period between 2001 and 2006 Balga, Nollamara and Westminster experienced a marked decline in Indigenous population, losing 54 (or 12.8% of its total Indigenous population), 73 (or 30.1%) and 20 (or 11.4%) Indigenous residents respectively; while Mirrabooka was the only suburb which experienced an increase in its Indigenous population, adding 21 Indigenous residents, equivalent to an 8.5 per cent increase (City of Stirling 2010a).



The steep decline of the Indigenous population in Nollamara is consistent with the housing affordability issues affecting the suburb, which were discussed earlier.

### ***Cultural and ethnic characteristics***

The sampling area is also characterised by a high degree of cultural and ethnic diversity, and this is reflected on the Census data on country of birth and language spoken at home.

#### **Country of birth**

The sampling area is home to a high proportion of overseas-born residents; according to data from the 2006 Census they represented 37.1 per cent of the total population (ABS 2007a), compared with 27.1 per cent in WA (ABS 2007b) and 22.2 per cent nation-wide (ABS 2007a). Within the sampling area, the proportion of overseas-born residents is markedly higher in Mirrabooka – where they represent 46.2 per cent of the population – than in the rest of the suburbs, with 31.9, 34.5 and 35.6 per cent in Balga, Nollamara and Westminster respectively (City of Stirling 2010a).

Table 5.3 shows the most common countries of origin cited by residents in WA 6061 on the 2006 Census and their comparison with WA and Australian figures (ABS 2008c, 2008b, 2008a). Vietnam, Sudan and the Former Yugoslav Republic of Macedonia were the most commonly cited overseas countries from non-English background, with residents born in those three countries representing a higher proportion of the population compared with state and national figures.

Table 5.3: Six most common countries of origin: Comparative data for WA 6061, WA and Australia.

<b>Main Response</b>	<b>WA 6061</b>	<b>Proportion of Total (%)</b>	<b>WA</b>	<b>Proportion of Total (%)</b>	<b>Australia</b>	<b>Proportion of Total (%)</b>
<b>Australia</b>	14,551	52.1	1,279,224	65.3	14,072,944	70.9
<b>England</b>	1,332	4.8	174,186	8.9	856,939	4.3
<b>Vietnam</b>	1,058	3.8	10,488	0.5	159,850	0.8
<b>Sudan</b>	754	2.7	2,020	0.1	19,049	0.1
<b>New Zealand</b>	577	2.1	47,332	2.4	389,463	2.0
<b>FYRM*</b>	510	1.8	2,990	0.2	40,655	0.2

\* Former Yugoslav Republic of Macedonia. Source: ABS (2008a, 2008c, 2008b).

Data on countries of origin vary by suburb and reflect past and more recent migration patterns. Mirrabooka was the suburb with the highest proportion of population born

in countries from non-English speaking backgrounds – 40.4 per cent of the population – while the rest of the suburbs had similar proportions – 20.9, 24.7 and 26.2 per cent of the population in Balga, Nollamara and Westminster respectively (City of Stirling 2010a).

Figure 5.4 shows the top 10 overseas birthplaces by suburb, and highlights the top three culturally and linguistically diverse (CaLD) communities in each of the suburbs. Vietnamese and Sudanese communities had a large presence across the suburbs in the sampling area. The Vietnamese community was the largest CaLD population in Mirrabooka and Nollamara – representing 7.9 per cent and 3.3 per cent of the population respectively compared with 0.5 per cent state-wide and 0.8 per cent in Australia (ABS 2008c, 2008b). The Sudanese community represented 3.0 per cent of the population in Balga and Mirrabooka, and 2.3 and 2.2 per cent in Nollamara and Westminster respectively, compared with 0.1 per cent state- and nation-wide (ABS 2008b, 2008c).

Table 5.4: Top 10 overseas birthplaces by suburb: Data for WA 6061.

<b>Top 10 Overseas Birthplaces</b>	<b>Balga Proportion of Total (%)</b>	<b>Mirrabooka Proportion of Total (%)</b>	<b>Nollamara Proportion of Total (%)</b>	<b>Westminster Proportion of Total (%)</b>
<b>Bosnia and Herzegovina</b>	-	2.4	-	-
<b>Burma</b>	<b>1.1†</b>	2.3	-	-
<b>FYRM</b>	<b>1.1†</b>	<b>2.7†</b>	1.5	<b>2.5*</b>
<b>Greece</b>	-	-	1.0	1.3
<b>India</b>	0.8	1.5	-	0.9
<b>Iraq</b>	-	2.5	0.8	
<b>Italy</b>	<b>1.1†</b>	-	<b>1.9†</b>	<b>1.9†</b>
<b>Malaysia</b>	-	1.5	0.9	
<b>Netherlands</b>	0.7	-	-	
<b>New Zealand</b>	2.4	1.4	2.0	2.2
<b>Philippines</b>	-	-	-	1.0
<b>Poland</b>	0.6	-	-	0.9
<b>South Africa</b>	-	-	0.7	
<b>Sudan</b>	<b>3.0*</b>	<b>3.0#</b>	<b>2.3#</b>	<b>2.2#</b>
<b>United Kingdom</b>	7.6	3.6	6.1	6.2
<b>Viet Nam</b>	<b>1.4#</b>	<b>7.9*</b>	<b>3.3*</b>	1.8

\* Largest CaLD community; # second largest CaLD community; † third largest CaLD community.  
Source: City of Stirling (2010a).

A trends analysis reveals that the Vietnamese population decreased between 2001 and 2006, with all four suburbs experiencing negative growths of 8.7, 18.2, 12.0 and 14.9 per cent in Balga, Mirrabooka, Nollamara and Westminster respectively. By

contrast, the Sudanese community experienced a marked increase since the 2001 Census: Mirrabooka experienced the highest growth, increasing its Sudanese community from only six residents in 2001 to 228 in 2006, while Balga went from 23 to 250, Nollamara from 24 to 172, and Westminster from 30 to 88 (City of Stirling 2010a).

### **Language spoken at home**

Data from the 2006 Census on the language spoken at home reflect the cultural and ethnic profile of the sampling area. Table 5.5 shows that the proportion of residents who spoke English only at home was markedly lower than state and national figures, with 59.4 per cent in WA 6061 compared with 81.8 and 78.5 per cent in WA and Australia respectively (ABS 2007a, 2007b). Vietnamese, Arabic and Macedonian were the most common languages spoken at home other than English (ABS 2007b, 2007a).

Table 5.5: Language spoken at home: Comparative data for WA 6061, WA and Australia.

<b>Main Response</b>	<b>WA 6061</b>	<b>Proportion of Total (%)</b>	<b>WA</b>	<b>Proportion of Total (%)</b>	<b>Australia</b>	<b>Proportion of Total (%)</b>
<b>English only</b>	16,576	59.4	1,603,038	81.8	15,581,333	78.5
<b>Vietnamese</b>	1,397	5.0	13,242	0.7	194,855	1.0
<b>Arabic</b>	1,044	3.7	7,698	0.4	243,662	1.2
<b>Macedonian</b>	864	3.1	5,668	0.3	67,836	0.3
<b>Italian</b>	622	2.2	32,895	1.7	316,890	1.6
<b>Cantonese</b>	324	1.2	16,049	0.8	244,553	1.2

Source: ABS (2007a, 2007b).

### **Socio-economic characteristics**

Based on data from the 2006 Census, WA 6061 was the area with the highest level of socio-economic disadvantage by postcode in the Perth metropolitan area (ABS 2006a); it was ranked 19<sup>th</sup> in WA – of a total of 328 postcodes – and 162<sup>nd</sup> nationally – of a total of 2,478 postcodes (ABS 2006a). By suburb, Balga had the highest index of socio-economic disadvantage, followed by Mirrabooka, Westminster and Nollamara, making them the first, second, third and fifth most disadvantaged suburbs within the City of Stirling respectively (City of Stirling 2010a).

## **Income**

Data from the 2006 Census reveal that persons aged 15 and over residing in WA 6061 had markedly lower incomes compared with state and national figures. In the sampling area, the median weekly individual income was \$374, compared with \$500 in WA and \$466 nation-wide, while the median weekly household income was \$731, compared with \$1,066 and \$1,027 state- and nation-wide respectively (ABS 2007a, 2007b).

## **Education**

Census data also reveal lower levels of education in the sampling area compared with state and national figures. A comparatively high 38.2 per cent of the population residing in the sampling area had a maximum educational attainment of Year 10 or below, compared with 23.4 per cent state-wide and 23.1 per cent nationally, and levels of non-school qualifications were markedly lower than state and national levels across all qualifications, from postgraduate degree to TAFE Certificate III/IV<sup>10</sup> (ABS 2008b, 2008a, 2008c).

## **Employment**

The sampling area was also characterised by a higher level of unemployment compared with state and national figures. According to data from the 2006 Census, 717 persons were unemployed in the sample area, or 6.3 per cent of the population, compared with a low 3.8 per cent state-wide, and 5.2 per cent nation-wide (ABS 2007b, 2007a).

## **Occupation**

Consistent with data on education levels, residents in the sampling area were mainly employed as labourers (18.2% of employed persons aged 15 years and over), technicians and trades workers (17.6%), and clerical and administrative workers (14.4%) (ABS 2007a). Table 5.6 shows that the sampling area counted a markedly higher proportion of labourers compared with figures for WA (10.9%) and Australia (10.5%). In contrast, professionals represented a low 11.4 per cent in the sampling area, compared with 18.6 per cent in WA and 19.8 nation-wide, while the proportion of persons employed as managers was half that of WA and Australia – 6.6 per cent compared with 12.5 and 13.2 per cent respectively (ABS 2007a, 2007b).

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<sup>10</sup> Highest TAFE qualifications.

Table 5.6: Occupation: Comparative data for WA 6061, WA and Australia.

<b>Occupation</b>	<b>WA 6061 Proportion of Total* (%)</b>	<b>WA Proportion of Total* (%)</b>	<b>Australia Proportion of Total* (%)</b>
<b>Labourers</b>	18.2	10.9	10.5
<b>Technicians and trades workers</b>	17.6	16.4	14.4
<b>Clerical and administrative workers</b>	14.4	14.5	15.0
<b>Professionals</b>	11.4	18.6	19.8
<b>Community and personal service workers</b>	10.5	8.9	8.8
<b>Machine operators and drivers</b>	9.8	7.3	6.6
<b>Sales workers</b>	9.4	9.4	9.8
<b>Managers</b>	6.6	12.5	13.2

\* Employed persons aged 15 years and over. Source: ABS (2007a, 2007b).

### **Home ownership**

Data on dwelling characteristics in the sampling area reveal a lower proportion of fully-owned dwellings – 22 per cent compared with 30.2 and 32.6 per cent state- and nation-wide respectively; and a higher proportion of rented accommodation – 37.2 per cent compared with 26.0 and 27.2 per cent in WA and Australia respectively (ABS 2007b, 2007a). In addition, there was a higher proportion of public housing, with more than double the proportion in the sampling area compared with state and national figures – 32.7 per cent compared with 14.7 and 14.9 per cent in WA and Australia respectively (ABS 2007a, 2007b).

### **Family characteristics**

The main sampling area had a higher proportion of persons who had never married, and who were separated or divorced compared with figures for WA and Australia. According to data from the 2006 Census, 41.5 per cent of persons aged 15 years and over residing in the sampling area were married, compared with 49.5 and 49.6 per cent in WA and Australia respectively; 37.7 per cent had never married, compared with 33.7 and 33.2 per cent; 15.1 per cent were separated or divorced, compared with 11.6 per cent state-wide and 11.3 per cent nationally; while the proportion of widowed persons was similar to state and nation figures – 5.7 per cent, compared with 5.1 and 5.9 per cent in WA and Australia respectively (ABS 2007a, 2007b).

In terms of family characteristics, data from the 2006 Census shows a higher proportion of one-parent families compared with state and national figures. Of the 6,995 families residing in WA 6061, 38.7 per cent were couple families with children

(compared with 45.1 and 45.3% in WA and Australia respectively), 33.1 per cent were couple families without children (compared with 38.3 and 37.2%), 25.8 per cent were one-parent families (compared with 14.8 and 15.8%), while there were 2.4 per cent identified as ‘other families’ (compared with 1.7% both state-wide and nationally) (ABS 2007a, 2007b).

### **Other characteristics**

The sampling area had a higher proportion of households without a car – 11.5 per cent of all occupied private dwellings (ABS 2008a), compared with 9.5 per cent nationally (ABS 2008b), and a low 6.9 per cent in WA (ABS 2008c).

Finally, data from the 2006 Census on Internet connectivity reveals that only 45.9 per cent of households in WA 6061 had Internet connection (ABS 2008a), compared with 63.2 per cent in WA (ABS 2008c) and 61.3 nation-wide (ABS 2008b).

### **Other suburbs**

As discussed early in this chapter, some study participants were recruited outside of the main sampling area (the rationale is discussed in Chapter 4). All participants recruited from suburbs other than those included in the main sampling area lived in neighbouring northern metropolitan suburbs: Koondoola, Girrawheen, Ballajura and Dianella were represented with two participants each, while Innaloo, Maylands, Karrinyup, Tuart Hill, Marangaroo, Lockridge, Bedford, and Beechboro were each represented with one participant.

Table 5.7 provides a list of the additional suburbs represented in the study, with an indication of their corresponding postcode, and their IRSD rank and decile among the total of 328 WA postcodes. The data show that WA 6064 – represented with five participants – had a high level of socio-economic disadvantage that placed it in the 2<sup>nd</sup> decile, and similarly Lockridge, Maylands and Beechboro had high levels of disadvantage. In contrast, WA 6018 – represented with two participants – was among the least disadvantaged (ABS 2006c).

Table 5.7: Additional sampling areas and their IRSD.

Postcode	Suburbs Represented in the Study	Participants (count)	WA IRSD* (rank)	WA IRSD* (decile)
WA 6064	Koondoola, Girrawheen, Marangaroo	5	45	2
WA 6066	Ballajura	2	191	6
WA 6059	Dianella	2	214	7
WA 6018	Innaloo, Karrinyup	2	272	9
WA 6051	Maylands	1	117	4
WA 6060	Tuart Hill	1	158	5
WA 6052	Bedford	1	223	7
WA 6063	Beechboro	1	126	4
WA 6054	Lockridge	1	78	3

\* Index of Relative Socio-economic Disadvantage. Source: ABS (2006c).

As discussed earlier, regardless of their suburb of residence, most participants had a strong connection with the main sampling area, as they attended medical centres, community health clinics and Aboriginal community-controlled health services located in the Mirrabooka Regional Centre.

## Conclusion

Located in the north metropolitan area of Perth, the main sampling area is characterised by a mix of low- and medium-density residential dwellings and a high proportion of public housing, and has limited public transport infrastructure. The Mirrabooka Regional Centre acts as a hub for community resources and public transport, and is currently being redeveloped to address access, connectivity and safety issues.

The main sampling area is home to a culturally diverse, young population, and has a comparatively high proportion of Indigenous residents. People living in the area are faced with considerable challenges: they earn lower incomes, have poorer education, are exposed to higher levels of unemployment, and are more likely to be employed in occupations which do not require qualifications. They are more likely to be unmarried and separated or divorced, and they are also more likely to live in one-parent families. Finally, people living in the main sampling area are less likely to have a car, and they are also less likely to be connected to the Internet.





## Chapter 6 – Diabetes Model of Care

*The person with diabetes must be his own doctor,  
nurse and lab technician.*

(HG Lawrence, co-founder of the British Medical Association,  
physician and person with diabetes)

### **Guidelines and principles of diabetes care**

Diabetes is a chronic, debilitating disease associated with severe complications (General Assembly of the United Nations 2007), and its care is complex and requires a systematic approach (IDF Clinical Guidelines Task Force 2005; Diabetes Australia 2010). At an international level, the International Diabetes Federation (IDF), recognising the complexity of diabetes care and the diversity of standards of clinical practice, developed an evidence-based *Global Guideline for Type 2 Diabetes* (IDF Guideline) based on the evidence from national and local guidelines from, among others, the US, Canada, the UK and Australia (IDF Clinical Guidelines Task Force 2005). Recognising the disparities in healthcare resources between countries, the IDF Guideline contains recommendations for three levels of care: standard, minimal and comprehensive care. Standard care is evidence-based cost-effective care that should be available to all people with diabetes; minimal care is the lowest level of care that anyone with diabetes should receive in healthcare settings with very limited resources; and comprehensive care includes the most up-to-date range of health technologies that can be offered to people with diabetes (IDF Clinical Guidelines Task Force 2005).

In Australia, the model of care for T2D is underpinned by two suites of *Evidence Based Guidelines for the Prevention and Management of Type 2 Diabetes* (NHMRC Guidelines), developed by the Diabetes Australia Guideline Development Consortium (DAGDC) and endorsed by the NHMRC. The development of the initial suite was initiated in 1999 and comprised guidelines on: primary prevention; case detection and diagnosis; blood pressure control; lipid control; prevention and detection of macrovascular disease; and detection and prevention of foot problems. This set of guidelines was the object of substantial additions and updates completed in 2009, including an update on the existing guidelines on primary prevention, and case detection and diagnosis; plus three additional guidelines on: diagnosis,

prevention and management of chronic kidney disease; blood glucose control; and patient education (DAGDC 2009).

The NHMRC Guidelines target public health practitioners, clinicians, diabetes educators and consumers, and focus on care processes and interventions primarily undertaken in the non-acute setting (DAGDC 2009). The guidelines contain a set of recommendations which are a general guide to appropriate practice, and they are underpinned by the following diabetes care principles:

- People with diabetes should have access to timely and ongoing care from a diabetes team;
- People with diabetes are entitled to access to opportunities for information, education and skills acquisition to enable them to participate optimally in their diabetes management;
- People with diabetes are entitled to access high quality health services regardless of their financial status, cultural background, or place of residence;
- For people with diabetes from community groups who may have special needs, for example, people from Aboriginal, Torres Strait Islander or culturally and linguistically diverse backgrounds and the elderly, diabetes care should be specifically tailored to overcoming access barriers and providing opportunities for optimising diabetes care and outcomes; and
- Diabetes teams should routinely evaluate the effectiveness of the care they provide (DAGDC 2009, 4).

The NHMRC Guidelines inform the *Diabetes Management in General Practice* guidelines (GP Guidelines). This national document – jointly developed and regularly updated by Diabetes Australia and the Royal Australian College of General Practitioners – contains a summary guide of current guidelines and recommendations on the management of T2D in the general practice setting, and includes a set of goals for the optimum management of diabetes that all people with diabetes should be encouraged to reach (Diabetes Australia 2010). The GP Guidelines also contain references to other relevant national guidelines, including: the *National Heart Foundation Guidelines* (Heart Foundation 2010); the *NHMRC Australian Alcohol Guidelines* (NHMRC 2009); the *Dietary Guidelines for Australian Adults* (NHMRC 2003a); and the *National Physical Activity Guidelines for Adults* (NHMRC 1999). The Dietitians Association of Australia has also published a set of evidence-based guidelines for the nutritional management of T2D (Dietitians Association of Australia 2006).

At state level, a document published by WADoH (WADoH Model of Care) provides a framework for the provision of coordinated diabetes prevention and management services in WA. Among the key objectives of the framework document are to: prevent and delay the onset of diabetes; prevent and slow the progression of diabetes complications; improve the quality of life of people living with diabetes; and ‘reduce inequities in service provision, particularly for Aboriginal people and other disadvantaged groups’ (WADoH 2008, 8).

The principles of care adopted by the NHMRC provide the foundation for the three key components of diabetes care: information and self-care education; on-going clinical care; and early detection and management of complications (DAGDC 2009).

## **Information and self-care education**

Self-management is the cornerstone of diabetes management, and diabetes education has long been recognised as a ‘vital and integral component of successful diabetes care’ (Colagiuri, Girgis *et al.* 2009, 7). Despite this recognition, national and international reports identified a lack of agreed benchmarks on diabetes education, which led Diabetes Australia to commission the development of a *National Consensus on Outcomes and Indicators for Diabetes Patient Education* (National Consensus Report) (Eigenmann and Colagiuri 2007), in preparation for the development of the NHMRC *National Evidence Based Guideline for Patient Education in Type 2 Diabetes* (NHMRC Patient Education Guideline) (Colagiuri, Girgis *et al.* 2009). The report identified three overarching goals of diabetes patient education: optimal adjustment to living with diabetes; physical health; and optimal cost (Eigenmann and Colagiuri 2007). Table 6.1 shows the key outcomes and indicators identified under each overarching goal, illustrating not only the complexity of diabetes care, but also the pivotal role of self-management and the breadth of skills required to achieve optimum clinical outcomes.

Table 6.1: Goals, key outcomes and indicators of diabetes education.

Goal	Outcome	Indicators
Optimal adjustment to living with diabetes	Knowledge and understanding	Diabetes knowledge; application of knowledge; problem-solving skills
	Self-management	Practical skills; medication taking; physical activity; appropriate eating; risk reduction; appropriate attendance for medical care; carrying diabetes identification; hypoglycaemia management; sick day management; hospital admission
	Self-determination	Self-efficacy; empowerment; coping skills; confidence in diabetes self-management; participation in goal setting and decision making
Physical health	Psychological adjustment	Well-being; quality of life; mental health
	Clinical outcomes	Physical (weight; BMI; blood pressure) Biochemical (HbA <sub>1c</sub> ; lipids; kidney function) Complications (frequency and severity of short-term complications; presence of long-term complications)
Optimal cost	Cost-effectiveness	Individual (out-of-pocket expenses; loss of income) Societal (cost of products, medication and services; financial burden of complications; loss of productivity)

Source: Eigenmann and Colagiuri (2007).

Based on the National Consensus Report, the NHMRC Patient Education Guideline makes the following recommendations (Colagiuri, Girgis *et al.* 2009):

- All people with diabetes should be referred for structured diabetes patient education;
- Diabetes education should be comprehensive and delivered in groups or individually and, where possible, by a multidisciplinary team; and
- Diabetes education should be culturally sensitive and tailored to the needs of socio-economically disadvantaged populations.

The WADoH Model of Care recommends that, as part of the optimal initial and long-term management, people with T2D should be provided with high quality information packages, tailored for location, cultural factors and special needs (WADoH 2008). In addition, the document states that accessible diabetes self-management education services need to be supported by streamlined referral processes (WADoH 2008), while the GP Guidelines recommend referring patients to a diabetes educator and a dietician at the time of diagnosis, and then as considered necessary by the patient, doctor or the diabetes educator (Diabetes Australia 2010). The importance of patient education is also recognised as a key element of the early

detection and optimal management of complications (WADoH 2008), and of sick day management (Diabetes Australia 2010).

Finally, the GP Guidelines recognise that diabetes education is on-going and needs to be continued for the rest of the person's life, recommending that diabetes knowledge, in particular self-management skills, be assessed regularly by GPs (Diabetes Australia 2010).

## **On-going clinical care**

The recommended model for optimal initial and long-term management of T2D in WA revolves around two key elements: a general practitioner-coordinated multidisciplinary management; and specialist services for the management of specific issues (see Appendix 15) (WADoH 2008).

### ***GP-coordinated multidisciplinary management***

In Australia, the medical care of T2D is predominantly carried out by general practitioners (GPs) (DAGDC 2009). The GP is the first point of contact and usually assumes responsibility for the overall management of diabetes (Diabetes Australia 2010); however, given its complexity, the management of diabetes requires a team approach (Diabetes Australia 2010) and the establishment of a partnership between the person with diabetes and the clinician (WADoH 2008).

The key elements of the on-going clinical care of the person with diabetes recommended in the GP Guidelines are an initial assessment of the person with diabetes, followed by an initial management plan, and regular follow-up reviews (Diabetes Australia 2010). A detailed assessment is required at first diagnosis, including: a history of specific symptoms, predisposition to diabetes, risk factors for complications, general symptom review, and lifestyle issues – including smoking, nutrition, alcohol, physical activity and occupation; a physical examination; and baseline investigations of renal function, lipids and glycaemia (Diabetes Australia 2010).

The initial management of diabetes recommended by the GP Guidelines revolves around a set of goals for optimum diabetes management that all people with diabetes are encouraged to reach (Diabetes Australia 2010). These goals (shown in Table 6.2)

provide specific target levels for blood glucose, glycated haemoglobin (HbA<sub>1c</sub>)<sup>11</sup>, lipid levels, renal function measures, blood pressure and BMI; and for lifestyle factors, such as cigarette consumption, alcohol consumption, and physical activity.

Table 6.2: Goals for optimum diabetes management.

Component	Goal
Blood glucose level	6.1 – 8.0 mmol/L (fasting)*
HbA <sub>1c</sub>	≤ 7%
LDL-C (High-Density Lipoprotein)	< 2.5 mmol/L#
Total cholesterol	< 4.0 mmol/L#
HDL-C (Low-Density Lipoprotein)	> 1.0 mmol/L#
Triglycerides	< 1.5 mmol/L#
Blood pressure	≤ 130/80 mm Hg†
BMI	< 25 kg/m <sup>2</sup> where appropriate
Urinary albumin excretion	< 20 µg/min (timed overnight collection) < 20 mg/L (spot collection) < 3.5 mg/mmol (albumin creatinine ratio; women) < 2.5 mg/mmol (albumin creatinine ratio; men)
Cigarette consumption	Zero
Alcohol intake	≤ 2 standard drinks (20g)/day (men and women)^
Physical activity	At least 30 minutes walking (or equivalent) 5 or more days/week (Total ≥ 150 minutes/week)

\* NHMRC National Evidence Based Guideline for Blood Glucose Control in Type 2 Diabetes 2009; # National Heart Foundation Guidelines; † NHMRC Evidence Based Guidelines for the Management of Type 2 Diabetes 2005; ^ NHMRC Australian Guidelines to Reduce Health Risks from Drinking Alcohol 2009. Source: Diabetes Australia (2010).

Achieving glycaemic control is at the core of diabetes management. Following the new target levels recommended in the NHMRC *National Evidence Based Guideline for Blood Glucose Control in Type 2 Diabetes* (NHMRC Blood Glucose Guideline) (Colagiuri, Dickinson *et al.* 2009), the GP Guidelines recommend a goal of self-monitored plasma glucose levels of 6.1–8.0 mmol/L preprandial (fasting) and 6.0–10.0 mmol/L postprandial (after meals). Long-term glycaemic control is monitored by measuring glycated haemoglobin (HbA<sub>1c</sub>), and the recommended target level is ≤ 7.0 per cent (Diabetes Australia 2010).

Although the aim of diabetes management is normal blood glucose levels (normoglycaemia) (Diabetes Australia 2010), the NHRMC Blood Glucose Guideline recommends that the potential harmful effects of optimising blood glucose levels – such as weight gain and increased risk of hypoglycaemia – should be considered when setting individual glycaemic targets, adding that fear of hypoglycaemia is

<sup>11</sup> Measure of blood glucose control over a period of approximately three months.

common in people with diabetes (Colagiuri, Dickinson *et al.* 2009). In this context, the NHRMC Blood Glucose Guideline recommends that self-monitoring of blood glucose (SMBG) should be considered in all people living with T2D, but the decision, and the frequency and timing should be individualised (Colagiuri, Dickinson *et al.* 2009); the GP Guidelines follow this recommendation, stating that the frequency of SMBG can be determined according to the individual's self-management goals (Diabetes Australia 2010).

Counselling on nutrition and physical activity is also a critical component of diabetes management as over 50 per cent of people presenting with T2D will initially achieve their blood glucose target levels through restriction of energy intake, increased activity and weight reduction (Diabetes Australia 2010). The GP Guidelines provide a series of recommendations on nutritional management around carbohydrate, fat and protein content: carbohydrates should contribute up to 50 per cent of the total energy intake, and people with diabetes should have one high fibre, low GI (glycaemic index) carbohydrate food at each meal; dietary fat should be less than 30 per cent of the total energy intake, saturated fats should be limited, and fried foods avoided; and protein should contribute 10–20 per cent of the total energy intake (Diabetes Australia 2010). The GP Guidelines recommend a trial of lifestyle modification – including increased physical activity, diet modification and weight control – of at least six to eight weeks before oral hypoglycaemic agents are considered (Diabetes Australia 2010).

The GP Guidelines note that multiple medications are needed to control the multiple risk factors associated with T2D, in particular hyperglycaemia, hypertension, dyslipidaemia, and increased thrombogenesis (clot formation). The use of hypoglycaemic agents is recommended if the healthy lifestyle trial is unsuccessful in controlling blood glucose levels, and the Guidelines note that most people with diabetes will require increasing doses and additional medications as their diabetes progresses, and in some cases insulin therapy may be required (Diabetes Australia 2010).

As part of the on-going clinical care of diabetes, the GP Guidelines recommend regular follow-up visits, which provide an opportunity for GP and patient 'to explore the patient's understanding, fears and concerns about diabetes' (Diabetes Australia

2010, 29). The quarterly review is a routine visit once glucose control is achieved. Its main aims are to discourage smoking, check weight and blood pressure, and provide an opportunity to review self-monitoring and any symptoms (Diabetes Australia 2010). Table 6.3 provides an overview of the recommended components of the quarterly review, including measuring HbA<sub>1c</sub> levels at least six-monthly (Diabetes Australia 2010), which is consistent with the NHMRC Blood Glucose Guideline (Colagiuri, Dickinson *et al.* 2009).

Table 6.3: Recommended components of diabetes care quarterly review.

<b>Component</b>	<b>Content</b>	<b>Conditions/Frequency</b>
History	Review SNAP (Smoking, Nutritional, Alcohol, Physical activity) profile	Quarterly
	Review patient's record of home testing and quality control results	Quarterly
	Foot symptoms	Quarterly
Examination	Check weight/waist	Quarterly
	Blood pressure	Quarterly
	Feet examination	If new symptoms or at risk
Investigation	Measure glycated haemoglobin (HbA <sub>1c</sub> )	At least six-monthly

Source: Diabetes Australia (2010).

The annual review provides an opportunity for more detailed assessment, re-establishing goals for self-management, and reviewing eating plan, lifestyle, home monitoring and treatment (Diabetes Australia 2010). Table 6.4 provides an overview of the recommended components of care of the annual review, which include a full physical assessment; lipid and renal function investigation; referrals; and immunisations.



Table 6.4: Recommended components of diabetes care annual review.

Component	Content	Conditions/Frequency
Full physical assessment	Cardiovascular system	Annually
	Peripheral nervous system	Annually
	Eyes	Annually
	Feet	Annually
Investigation	Lipids: triglyceride; HDL-C*, LDL-C# and total cholesterol	Annually if below target, more frequently if being actively treated
	Renal: microalbuminuria and plasma creatinine	Annually if below target, more frequently if being actively treated
Referral	Ophthalmologist / optometrist	Second-yearly with no retinopathy, more frequently if abnormal
	Diabetes educator, dietician, podiatrist	If patient has or has developed a problem requiring review
	Pharmacist	Home Medication Review if patient is likely to have problems with medication
	Oral health professional	Especially if periodontal disease is present
Immunisations	Influenza	Annually
	Pneumococcal	Single dose and revaccination after 5 or 10 years (depending on age and Indigenous status)
	Tetanus	Booster at age 50 (unless booster has been given within 10 years)

\* High-Density Lipoprotein; # Low-Density Lipoprotein. Source: Diabetes Australia (2010).

An important aspect of the annual review is that it provides an opportunity for referral to specialist services and allied health professionals if required (Diabetes Australia 2010); these referrals form the basis of the recommended team approach to diabetes care.

### ***Multidisciplinary team***

As discussed earlier in this chapter, the GP Guidelines recommend a team approach for the management of T2D, where the patient is the central member, and the GP coordinates a team of clinicians and allied health professionals (Diabetes Australia 2010). This multidisciplinary team includes a wide range of health professionals, as illustrated in Figure 6.1:

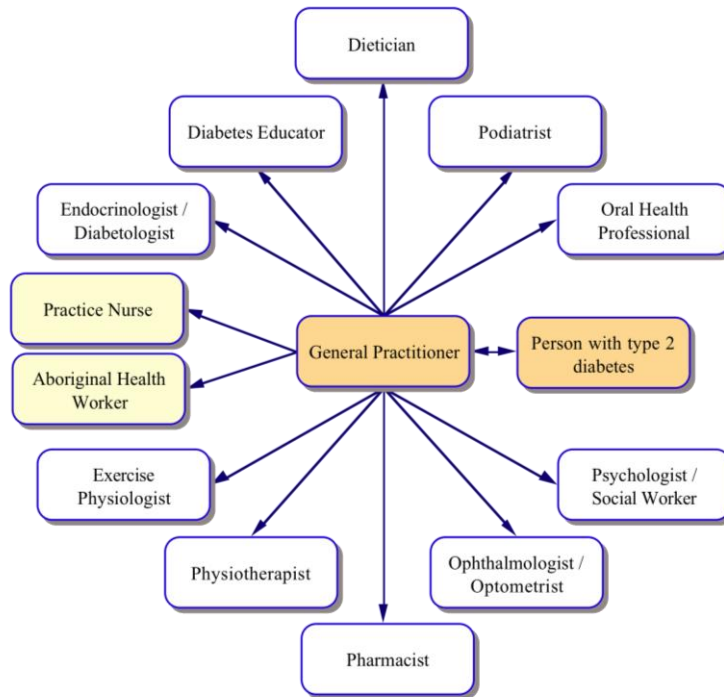


Figure 6.1: Multidisciplinary diabetes team. Source: Diabetes Australia (2010) and WADoH (2008).

Practice nurses and Aboriginal health workers (AHWs) (where available) play a pivotal role in the management of diabetes: practice nurses work within the general practice setting and can contribute to patient education, facilitate adherence to treatment, and also assist in patient assessment (WADoH 2008); and AHWs play a vital role in the prevention and management of diabetes in Aboriginal people, providing culturally appropriate and practical support and counselling (Diabetes Australia 2010). In addition, the following health professionals are part of the team approach to diabetes (WADoH 2008; Diabetes Australia 2010):

- Endocrinologists or diabetologists provide specialist services to address specific issues;
- Diabetes educators provide self-management education services;
- Dietitians provide nutritional recommendations;
- Podiatrists play an important role in prevention, early detection and management of diabetes-related foot problems;
- Physiotherapists and exercise physiologists provide advice on the implementation of a physical activity program;

- Ophthalmologists and optometrists play an essential role in the early detection and management of diabetic retinopathy and other eye problems; and
- Psychologists and social workers can provide counselling on issues associated with adjusting to disease, behavioural change, and anxiety and depression.

Finally, the GP Guidelines recognise the role played by two additional health professionals not mentioned in the WADoH Model of Care: oral health professionals – as dental and periodontal problems are common in people with diabetes – and pharmacists (Diabetes Australia 2010).

## **Early detection and management of complications**

The third key component of diabetes care adopted by the NHMRC in its Diabetes Guidelines is the screening for and appropriate treatment of diabetes complications (DAGDC 2009). Factors complicating the management of diabetes may occur independently from diabetes (for example, an intercurrent illness), or may result from the diabetes process, (for example macrovascular or microvascular disease) (Diabetes Australia 2010). The recommended model of early detection and optimal management of diabetes complications endorsed by WADoH includes the following key elements (2008):

- Awareness of diabetic complications, involving health promotion and patient education to ensure that people with diabetes understand the nature of the long-term complications of diabetes, how these complications can be prevented, and the importance of regular assessment for early detection;
- Accessible, coordinated complication detection and management services;
- Guidelines and protocols for the detection and management of diabetic complications; and
- Optimal specialist services.

The WADoH Model of Care recommends that a coordinated approach to complication detection management services should include: ophthalmology and optometry services; general and specialist podiatry; multidisciplinary specialist screening services; liaison with renal, cardiovascular and other specialist services; and proactive services to ensure comprehensive regular screening for complications in Aboriginal people and other high risk and vulnerable groups (WADoH 2008).

The GP Guidelines include recommendations for the prevention, early detection and management of macrovascular disease, hypertension, dyslipidaemia, renal damage,

eye damage, foot problems, and neuropathy. The Guidelines also address medication issues, including non-adherence and drug interactions; and recommend a review of medication adherence as part of the annual cycle of care, and the consideration of a Home Medication Review<sup>12</sup> (Diabetes Australia 2010).

Finally, the implementation of guidelines and protocols for the detection and management of diabetic complications is recommended, including the use of registers, recall systems and audit processes to ensure that assessments for complications are carried out; and the use of general practice management plans (GPMPs), multidisciplinary team care arrangements (TCAs), and Medicare rebates for allied health services (WADoH 2008). GPMPs are documented plans developed by the GP and the patient which incorporate the patient's needs, goals, how these are going to be achieved, and reference to any resources needed; and TCAs are an extension of the GPMP, which detail the allied health workers who will implement the GPMP – typically dietitians, diabetes educators, podiatrists or physiotherapists (Diabetes Australia 2010).

## **Conclusion**

The recommended model of care for the management of T2D is complex, and requires a multidisciplinary approach and the provision of adequate self-management education and resources to achieve optimal outcomes. GPs play a central role in the on-going management of diabetes, and in the early detection and management of complications; and coordinate a multidisciplinary team including specialists and allied health professionals. Self-management is paramount to optimal diabetes management; and on-going clinical care includes the development of a management plan in partnership with the patient, and quarterly and annual reviews to ensure that patients meet recommended target levels for optimal management.

Given the complexity of the model of care and its reliance on a wide range of health services, and the pivotal role of self-management, the question for this research is whether this model accommodates the needs of disadvantaged populations.

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<sup>12</sup> Designed to assist individuals living at home to maximise the benefits of their medicine regimen and prevent medication-related problems; it is conducted by an accredited pharmacist and requires referral by a GP.

## **Chapter 7 – ‘Doing the Right Thing’: Experiences and Attitudes towards Self- Management**

In this chapter, I present the findings relating to participants’ attitudes towards and experiences of self-managing their disease. The results presented here relate to the study’s first objective:

To explore the attitudes and experiences of disadvantaged persons living with T2D with respect to living with and self-managing their disease.

All direct quotations included in this and the next three chapters are presented in italics and contextualised by the use of a pseudonym followed by an indication of participant’s age, diabetes management regimen, and length of diagnosis.

### **Diet: The central component of diabetes self-management**

Participants regarded adopting a healthy diet as the main component of their management regimen. The data on diet represented a substantial proportion of participants’ narratives around self-management, both in terms of volume, and in terms of the number and complexity of emerging themes. The data showed that food choices and diet were not the result of individual choice and preferences only; rather, eating emerged as a social practice mediated by a set of circumstances surrounding participants from the time the food was purchased, through meal preparation, to the moment meals were consumed.

Participants’ narratives showed a common understanding of what constitutes a ‘healthy diet’, and a good knowledge of the dietary guidelines for a person with diabetes. Despite participants’ understandings and knowledge, access to healthy food was not always realised. Participants’ experiences pointed to two main access issues: the dependence on others for the provision of food and meal preparation; and the challenge of accommodating the cost of food within a tight income. Participants’ accounts also highlighted the importance of the social context in which meals are consumed, as they often discussed food and eating in the context of family and social settings.

## ***Eating the ‘right food’***

Participants viewed having a ‘healthy diet’ – which they also referred to as ‘healthy food’, the ‘correct food’ or the ‘right food’ – as a necessary requirement for a person with diabetes. Their narratives showed a high level of agreement around what constitutes a ‘healthy diet’, regardless of whether they viewed their own diet as complying with the requirements of a ‘healthy diet’ or not. According to participants’ narratives, having a ‘healthy diet’ involved cutting back on sugars and fatty foods, and increasing the consumption of fruit and vegetables. Drinking water was identified as a healthy habit, while low-sugar soft drinks were identified as a healthier alternative to regular soft drinks. Participants also identified a number of ‘healthy’ cooking techniques which included using little or no oil or margarine, and steaming and poaching. In contrast, deep frying was widely identified by participants as an unhealthy cooking practice.

Despite the common understandings around ‘healthy foods’, participants’ narratives revealed a wide range of diets and eating habits. Most accounts, however, had in common the notion of ‘change’. The majority of participants acknowledged that their diet had changed, often significantly, since their diagnosis; and the main changes reported included reducing the amount of fat, reducing the amount of sugar, and eating smaller portions.

Participants’ narratives showed that many had successfully implemented strategies to reduce their fat intake. These strategies included: changing their shopping habits, for example buying lean meat, skinless chicken, low-fat margarines and reduced-fat biscuits; and changing their cooking techniques, for example, using less oil, using spray oil instead of regular oil, cutting the fat off meat, and pulling the skin off chicken. Liz, a participant whose narrative revealed a high level of self-efficacy and good glycaemic control, provides an account that highlights some of these cooking techniques:

*I don’t cook in fat. When I do a roast or anything, I just put it on the tray, like the potatoes on the baking tray, and spray it and cook it that way... fat like we used to have when we were kids and it all dripped all over the place... And I steam my vegetables, and I’m not a big fat eater, I don’t spread a lot of margarine or anything.*

[Liz; 60s; tablets; diagnosed four years]

In her account, Liz alludes to the old style of cooking when she refers to her childhood; most participants associated these ‘old ways’ with cooking in oil and fatty foods, and, thus, identified them as ‘unhealthy’.

Bridget, who was interviewed with her Indian-born husband Cecil, discussed some of their cooking practices. Bridget talks about the technique she now uses to cook curries, which prompts an affectionate exchange between husband and wife:

*Bridget: as far as diet's concerned, I'm a bit sneaky when I cook, if he's not looking, uh... I don't use oils or anything. And he loves my curries, but he still doesn't know to this day what I do.*

*Cecil: yeah, I caught her. [...] No, I caught her the other day, and I didn't say anything because...*

*Bridget: he actually caught me.*

*Cecil: she cooks a damn good curry, and she cooks a damn good meal.*

*Bridget: 'cause he fries it up, whereas I put that much water in the bottom and that's my base, and then I go from there. There is no oil or anything.*

[Bridget; 40s; insulin; diagnosed six years. Cecil; 50s; insulin; diagnosed five years]

Being ‘sneaky’ in the kitchen is also something which Sheryl, who lives with her husband and their adult son and who reported being on a diet-only regimen, refers to when discussing her cooking techniques. Although referring to her use of a specific product – a low-fat salad dressing – Sheryl’s comment reveals her high level of self-efficacy around diet:

*You know, I buy low-fat stuff now, and I just hide the labels [...] See, when I do coleslaw or potato salad, and that sort of thing, I just... I do buy the low fat. I've even been known to buy the low-fat stuff and put it in the other sort of container, you know! [...] You've got to be sneaky, as well as wise.*

[Sheryl; 60s; diet; diagnosed one year]

Paul, who, like Sheryl, reported being on a diet-only regimen, described himself as ‘disciplined’ with regard to his diet. Paul lives alone, and his account revealed his good cooking skills and high level of self-efficacy. During the interview, Paul described a number of techniques he used to minimise his fat intake, for example, dripping the fat out of salami by placing it in the microwaves on brown paper. Paul describes other techniques he has adopted:

*All my meat I'll buy is lean, you know. I make stews out of it, and if there's fat I'll cut it off. Uh... I've got a horror of fat; not that it tastes bad, but... A friend of mine says, 'well you can't eat mince without fat'. I say, 'well, good mince costs about ten, twelve dollars a kilo'. I say, 'I couldn't eat that stuff, because it's got fat'; so I drain fat out of everything. When I get mince, I grill... put it in the grill and all the fat runs out, if there's any.*

[Paul; 80s; diet; diagnosed 18 months]

Paul reveals his 'horror of fat', a sentiment that was echoed, even if it was not expressed in such strong terms, by other participants. Some participants reported feeling physically unwell after consuming fatty foods, which might help explain why participants' accounts suggested that giving up on fatty foods was more easily achieved than letting go of sweets and sugary foods. For example, Mandy, who lives by herself and reported good glycaemic control, recalls a recent episode when she had a meal with her mother:

*Two weeks ago we went to have lunch, and I ordered lasagne, and I shouldn't have because after eating it I felt quite sick because of the fat content, from the cheese I think, yeah... Me stomach can't tolerate fatty foods anymore. At the time I enjoyed it, but me stomach pays me back [laughs].*

[Mandy; 50s; tablets; diagnosed two years]

Similarly, Liz, again referring to the 'old ways' of cooking when she was growing up, comments on how she feels after eating fatty foods:

*I mean, when we were growing up, everything was cooked in fat and whatever, but I mean that was it, and you got used to it. But now if I go to someone's place and they cook their meat in fat you can feel it in your mouth, you know.*

[Liz; 60s; tablets; diagnosed four years]

Most of the accounts above were reported by participants whose experiences suggested a high level of self-control and self-efficacy with regard to their diet. Their accounts revealed that they had achieved a balance in their diet, where changes had been implemented and incorporated into their daily routine. Dot, an Aboriginal participant who described her diet as 'pretty healthy' and who lives with her son, gave a detailed account of her diet which conveys this sense of balance and routine:



*I try to eat as healthy as possible. I eat my cereal in the morning, uh... I have the HiLo<sup>13</sup> milk. Uh... I don't tend to eat snacks, I'm not a person that eats snacks, I'm not a picker of food. Lunchtime is mainly just a sandwich, because I find that night-time is my main meal, because I like to have a meal with my son at night-time, so I try and eat healthy, cook healthy. Uh... I eat lots of salads, you know, uh... well, in the summer-time is mainly salads, but in the winter-time is just, you know, vegetables. We eat a lot of yoghurt, we have yoghurt at night-time; we're not into sweets, so it's mainly we have a meal that's yoghurt at night-time. Uh... but basically I eat, you know, pretty healthy food.*

[Dot; 70s; insulin; diagnosed 35 years]

Similarly, Paul describes his eating habits:

*I use the medium milk, not skimmed, but in between. I don't eat lots of ice-cream. I'll have a little bit of chocolate in moderation, but often daily, and at a routine time, after tea [...]. I split my breakfast up. I'll have one breakfast at six o'clock in the morning, and one at eight o'clock, you know. So I'll have my Weeties in the morning when I let the cat out, and then, uh... my Weet-Bix<sup>TM14</sup>; and then about eight, half past eight, I'll have my toast; and I'll have two sandwiches instead of four, two slices of bread instead of four, so I changed that. I eat more often, but not more.*

Later in the interview, Paul revealed that a severe cardiac episode 20 years earlier had resulted in radical lifestyle changes. Paul's comment provides an insight into the reasons driving his disciplined approach:

*My diet changed after I was discharged from hospital for a severe heart attack, but a very severe one, complete blockage, you know... and that gave me a scare. I stopped smoking, I stopped everything else, and now I watch what I eat, I knocked back cream, I knocked back... too many, lots of things, because... so I did make a change.*

[Paul; 80s; diet; diagnosed 18 months]

For many participants, however, adjusting to the requirements of a 'healthy diet' was still work in progress, and their accounts tended to be dominated by the foods they were not allowed to have, rather than by those they had incorporated to their diet. Tony, who has been a widower for several years and lives with his son, talked about his efforts to make changes to his diet, and in his account the verb 'try' appeared often. During his interview, Tony talked about 'trying to stay away from meat and fatty foods', which he perceived as unhealthy; and 'trying to eat apples' and 'trying

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<sup>13</sup> Reduced-fat, high-calcium milk.

<sup>14</sup> Wholegrain wheat breakfast cereal.

to eat porridge', which he perceived as healthy. Tony reflects on his attempts at incorporating some healthier choices to his diet, and his account suggests that those attempts are not always successful:

*I try and stay away from bikkies and stuff like that. I just get the plain bikkies, you know, without the, you know, the cream. Uh... just the plain biscuits, you know, uh... I try, anyway. But now and again I get a bit silly, and, you know, buy chocolate, but I'm not a very big chocolate eater anyway.*

[Tony; 50s; tablets; diagnosed 10 years]

Similarly, Peter, who during the interview came across as being somewhat confused about his dietary requirements and who lamented not receiving any guidance from his GP, talked about changes he was planning to make to his diet, for example, eating wholemeal instead of white bread. Peter's account – punctuated by references to books he had read – suggested that his beliefs around healthy food were influenced by information of which he was still trying to make sense. Peter reflects on the hardest aspect of his self-management:

*Peter: it would have to be the diet. Uh... myself I didn't know for ages that white bread, potatoes... there are lots of foods out there that turn straight into glucose, which then, basically it's just sugar.*

*Interviewer: and you found out about those things by reading?*

*Peter: yeah, through the Atkins Diet<sup>TM15</sup>. I found out a lot on that. It's astounding actually what some foods do. I try and eat lots of vegetables, fruit, and very small proportion of meat, tuna or fish is good for me, but stay away from saturated fats... saturated fats... what's the other fats?*

*Interviewer: transfats?*

*Peter: transfats, yeah.*

[Peter; 50s; tablets; diagnosed seven years]

Some of the barriers to adopting a healthy diet reported by participants were based around participants' emotional relationship with food. In participants' narratives, eating was a practice which went beyond the mere nourishment of the body. Food appeared as something which was enjoyed, liked, disliked, loved or hated. Participants often used terms of delight to talk about their favourite foods: Lorraine, for example, declared herself a 'lover of Pavlova<sup>16</sup>', while Paul confessed he had 'a bit of a leaning towards chocolate' and a 'soft spot for cakes'. Participants also

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<sup>15</sup> Weight-loss diet program based on high protein, high fat and low carbohydrate intake.

<sup>16</sup> Popular Australian meringue dessert topped with cream and fruits.

expressed their dislike of certain foods in emotive terms, and while Paul declared ‘I’ve got a horror of fat!’, Mandy expressed her dislike of cauliflower thus: ‘I can’t stand cauliflower, yuck!’.

In this context, giving up favourite foods and resisting cravings were challenges to participants’ will-power and self-control, and barriers to achieving a healthy diet. Many participants reported missing favourite foods, and most referred to one or two specific foods they missed the most, for example, toast, ice-cream or chocolate – the single foodstuff most often mentioned. Lorraine’s account of her experience of implementing changes to her diet highlights the central role of eating in her life and her emotional attachment to certain foods. During her interview – at just over two hours, the longest session – Lorraine made frequent references to all the foods she missed, which included chocolate, rocky-road, Pavlova, ‘pudding mayonnaise’, and ‘cream of curry chicken’. Lorraine often referred to the unfairness of her predicament, and in the following account she describes how she is still ‘learning to give things up’:

*I’ve got grandchildren and they like hamburgers, you see, but I’m not allowed them. I can have a sandwich, so they get me sandwich and they sit there eating Hungry Jack’s® or McDonald’s® hamburgers, and I can’t eat them. And it just doesn’t seem fair [chuckles] that you have to give up, you know, things you’re so used to growing up, and... I’m still learning to give things up, you know, it’s a little hard. I’ve given up Coke, no... yes... not fully, I haven’t, I will still have a little glass now and then, if the kids haven’t got to it first, I can have a little glass. But I will always leave lemonade in the fridge, and that’s sugar-free. But they like that too... [chuckles]. And they’ve got lollies over there [points to a corner of the room], ‘cause they’re for my great-grandson, and they’re bananas. But I don’t eat those...*

[Lorraine; 70s; tablets; diagnosed three years]

Lorraine’s comment reveals her emotional relationship with food, and the connection she establishes between certain foods and the good times she enjoys with her grandchildren, which make it harder for her to make adjustments to her diet.

Cravings were also reported by participants as a challenge to their will-power, and the craved foods were mostly ‘something sweet’, often chocolate. Sheryl, whose account revealed a good level of self-efficacy with regard to diet and exercise, described her impulse to eat certain foods as ‘crazes’, and she laughs as she vividly describes what it feels like to have a ‘sweet craving’:

*If I want something sweet, I have it. And you get these sweet cravings where you find there's nothing in the house; you just about rip the fridge door off!*

[Sheryl; 60s; diet; diagnosed one year]

Some participants seemed to accept that cravings would occur at some point and their accounts suggest that they viewed occasionally giving in or having a treat as something natural. Liz comments on how her diet has changed since her diagnosis and touches on the issue of cravings:

*Basically it's watching what you eat. Yes, you do get cravings for sweets, and I find it easier to have it than let it go so that you eat up the whole packet of biscuits, you know.*

Later in the interview, Liz's account confirms her self-control, as she rather humorously describes the attitude of a person close to her who also has diabetes:

*One of our girls that we looked after, her father is a diabetic. He's got cardiovascular problems and everything else, the only thing he's not is pregnant, but anyway... And he's not satisfied to have one slice of something, he's got to have half the cake, and he eats and everything is cooked in fat, and you think, excuse me, uh... why would you be doing that, I mean, if you have cardiovascular problems, in any case you shouldn't be eating fat, and that's not good for your diabetes. But, yes, everybody feels like something sweet now and again, but you don't have to have half a Pavlova at one sitting!*

[Liz; 60s; tablets; diagnosed four years]

Paul, one of the few study participants whose weight appeared to be within a healthy range, echoes Liz's attitude when he provides the following piece of advice:

*My advice to anybody who's got diabetes is 'don't worry about eating a lolly occasionally'. I do like a bit of cake, you know. I've got a soft spot for cakes too. But I'm not a person like some people who keep on eating and eating and eating. I'll have a piece of cake and that's it. Would I like more? Yes, I could eat more, but I won't.*

[Paul; 80s; diet; diagnosed 18 months]

The issue of cravings and how to negotiate a balance between the regimented aspect of diet management, and the need for an occasional 'treat' came up during the non-Indigenous focus group. An unprompted exchange between Christine and Anne, two participants who during the session seemed to develop some rapport perhaps due to the similarities in their experience of disease, illuminates this point. Anne begins by

reflecting on the changes to her lifestyle, which prompts the following exchange with Christine:

Anne: *you alter your way of life... but then, you know, now and again, because... I think it should be alright.*

Christine: *it is alright, because it's your quality of life that counts.*

Anne: *yes.*

Christine: *and you live... and if you're going to go and splurge... and you know why.*

Anne: *yes.*

Christine: *and that's OK too, because so long as you don't do it all the time, your BSL<sup>17</sup> won't stay high all the time... Be prepared for it, you know...*

Anne: *and it's not every day you're going to a birthday party or anything like that. You should be able to a point...*

Christine: *but don't overindulge. I reckon don't deprive yourself... you pay a price, but make sure you keep it up.*

Anne: *yeah.*

[Anne; 50s; insulin; diagnosed 10 years. Christine; 60s; tablets; diagnosed 20 years]

The exchange is revealing, as both Anne and Christine appear to be seeking each other's validation of their own experience, as they strive to find a balance between what they perceive as 'overindulging' and 'depriving' themselves.

Resisting the temptation to give in to cravings was particularly challenging for those participants who tended to associate food with a specific emotional state and who reported using food to comfort themselves when stressed or upset. As Mary, an Aboriginal woman who took part in a joint interview and who reported having weight issues, put it succinctly:

*Well, I eat chocolate when I get stressed.*

[Mary; 60s; insulin; diagnosed 20 years]

Similarly, Patricia, who reported struggling with her weight and having been on several diets, disclosed her emotional relationship with food at the beginning of her interview. When asked whether there have been many changes to her diet, Patricia replies:

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<sup>17</sup> Blood sugar level.

*Yeah, a little bit, but not that much. I mean, even though I'm a big person, I've never been into eating a lot of fat, like meat or anything like that. My problem is, when I get upset, I eat. [...] I do things I shouldn't do, like eat what I shouldn't.*

[Patricia; 60s; insulin; diagnosed six years]

Cecil, who was born in India, provided an account of his craving of curry that encapsulates participants' experience of the comfort provided by food, while also pointing at the facilitating role played by his wife:

*Sometimes I'll feel so ill in bed, like a little baby, I want a curry but I can't get it. She'll [my wife] get up and do it! [laughs].*

[Cecil; 50s; insulin; diagnosed five years]

Cecil's comment is also significant because it highlights the cultural dimension of food and eating. Three interview participants were born in India and one in Burma, and their accounts around diet revealed references to favourite meals and traditional ways of cooking from their home countries. This subsample provided the opportunity to explore the challenges involved in giving up or reducing the intake of rice, one of the staples of the traditional Indian diet and one of the foods whose consumption is not recommended for a person with diabetes. Rose, who was born in Burma and whose husband Michael was born in India and raised in Burma, reported a high level of self-control with regard to her diet. Rose reported having introduced brown rice in her diet, and having managed to convince her husband Michael to give up Thai rice, which she understood to be full of starch, and replace it with Basmati rice, which she perceived as being a healthier option. Later in the interview, Rose discusses other changes to her diet, and she refers to the traditional Burmese diet, which shaped her eating habits when she was growing up:

*We, Burmese tend to eat too much oil; and veggies [...] back home we never used to eat much veggies, you know.*

[Rose; 60s; insulin; diagnosed 20 years]

The experience of Martin, a participant who was also born in India and reported very poor glycaemic control, and whose narrative was dominated by his profound sense of social isolation, highlights the challenges of giving up staple foods. Martin, who reported having been diagnosed for 10 years, recalled how hard it had been to make changes to his diet and, in particular, to give up rice, and explained that he had only given it up when the ophthalmologist had detected the early signs of diabetic

retinopathy two years earlier. Martin reported that he would now have rice only occasionally, ‘as a treat’.

### **Access issues around food**

Diet and eating are not the result of personal choices and will-power only. Participants’ narratives revealed two major access issues that influenced their eating habits and everyday diets: firstly, depending on others for shopping, cooking and food provision; and secondly, the perceived high cost of food in general, and of fruit and vegetables, and diabetes-friendly products, in particular.

### **Dependence on others for food provision**

While this was not an issue which was unique to Indigenous participants, they were more likely to report depending on relatives or others around them for food shopping and meal preparation than non-Indigenous participants. The majority of Indigenous participants who took part in the interviews conducted at Derbarl Yerrigan reported relying on close family members for food shopping, as they did not have a car or a driving licence, and had mobility issues that prevented them from walking to the local shops or using public transport to access supermarkets. Their narratives revealed that most were socially isolated and would not usually leave their home unless they were taken somewhere by either a family member or Derbarl Yerrigan staff. Frances, an Aboriginal participant who reported very poor glycaemic control, provides an account of her shopping routine which is representative of that of other Indigenous participants:

*Well, I’ve got to wait until five o’clock when [my daughter] gets home, and then we go shopping. [...] Our main days we go on Saturdays and Thursday night. [...] ‘Cause otherwise I’ve got to wait until she comes home. If I’ve got nothing to eat I still have to wait until she comes home; I can’t walk up the shops.*

[Frances; 70s; tablets; diagnosed 40 years]

Similarly, Gail, who described her diet as ‘fairly good’ and partly attributed this to having a ‘strict’ daughter, describes how she gets her shopping done, and her account reveals the network of people she relies on for food provision:

Gail: *somebody always takes us, if it's not Derbarl, uh... I've got nieces.*

Interviewer: *oh, good.*

Gail: *yeah, and I've got a grandson, I've got a daughter, and I've got a good, a very good son-in-law. I'm very lucky.*

[Gail; 70s; insulin; diagnosed 20 years]

At the extreme end of dependency were those participants who reported not cooking for themselves, and whose meals were provided to them either by family members or by welfare agencies. Of the 11 Aboriginal women who took part in the interviews held at Derbarl Yerrigan, five reported that they did not do their own cooking, and their narratives suggested that some were not provided with food which met their dietary requirements. Lyn, who is visually impaired and looked very frail at the time of the interview, explained that she had not been cooking because she had lost the use of her hands. Lyn comments on her meals:

*Well, my daughter looks after me, and she gives them [meals] to me every now and again when I feel like eating. But I eat... I eat when I feel like eating, because one time I went off my food; in fact, I'm too skinny now, I'm just a bag of bones almost [chuckles].*

Later, she adds:

*I like fish, but she [my daughter] won't buy it for me.*

[Lyn; 80s; tablets; no data available on length of diagnosis]

Similarly, Rachael, who has two grandsons living with her, reported not being able to cook because she had had a stroke and had lost the use of her right arm. Rachael, who reported struggling with her weight, talks about her diet:

*The kids bring take-aways. I just can't say no, it's horrible. I just can't control it. [...] I just couldn't go on a diet. I mean, my grandson cooks eggs and bacon when he's hungry, and I end up eating it, which I shouldn't, I know, but... I just can't control myself.*

Rachael's comment conveys a sense of powerlessness at her lack of self-control, made more acute by her realisation that she is eating the wrong food. Later, when discussing her daily meals, Rachael explains:

*My grandson cooks meals, or my daughter-in-law, so they cook it overnight and then warm it up.*



When asked if they cook differently to accommodate her dietary needs, Rachael tentatively, but unconvincingly, responds:

*Yeah, sometimes, yeah...*

[Rachael; 60s; insulin; diagnosed 20 years]

Rachael's comment triggered an unprompted exchange with Cathy which highlights the issue of depending on welfare agencies for the provision of food. Cathy, who reported being in remission from cancer, asks Rachael:

Cathy: *do you do Meals on Wheels*<sup>18</sup>?

Rachael: *no, I can't afford it.*

Cathy: *it's very expensive.*

Interviewer: *the Meals on Wheels?*

Rachael: *they're very expensive.*

[Cathy; 70s; tablets; diagnosed 12 years. Rachael; 60s; insulin; diagnosed 20 years]

*Meals on Wheels* was mentioned by several participants, and the issue of its high cost was also raised by Rhonda and Jim, a married couple who were interviewed together. Jim and Rhonda talk about accessing this program, and their account reveals that they now have an outstanding bill with the organisation delivering the meals:

Jim: *while Rhonda was in hospital, I had to access Meals on Wheels, uh... which was very good. They were... at least I had one decent meal a day. Uh... we tried to continue on...*

Rhonda: *it was too expensive.*

Jim: *... but it got too expensive for two people. [...] Based on eight dollars per hit, daily...*

Rhonda: *three days a week... and it got to be expensive. We've got to pay that bill now, 'cause they won't give it to us now until we pay it back.*

Rhonda and Jim's account provides an insight into the lack of food security facing those struggling to make ends meet on low incomes. At the beginning of the interview, Rhonda and Jim said very little about their diet; even when prompted on specific details, both remained guarded. As the interview unfolded and they became more comfortable, they disclosed that for the last five months they had been accessing a food bank fortnightly. It has to be noted that neither Jim nor Rhonda

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<sup>18</sup> Government-subsidised program delivering meals to frail aged and disabled people living in the community.

were very articulate, and throughout the interview I had to prompt them often to clarify their accounts. Despite their limited ability to articulate their views, they were both keen to discuss this issue:

*Jim: a lot of welfare agencies are not aware of the needs for diabetic food.*

*Rhonda: that's... that's something.*

*Interviewer: so what happens is that they don't have what you need?*

*Rhonda: they have things that are not for diabetics. [...]*

*Jim: no, it's not the proper diabetic diet.*

*Interviewer: is that food banks and places where you can...?*

*Jim: yeah, food banks.*

*Rhonda: sometimes they put sausage rolls and pies in and...*

*Interviewer: alright.*

*Jim: ... pastries... that sort of...*

*Rhonda: that's something we don't do...*

[Rhonda; 60s; tablets; diagnosed three years. Jim; 60s; tablets; diagnosed eight years]

Jim and Rhonda's account provides an insight into their lack of choices and control over their diet due to their extreme financial difficulties, and highlights their sense of powerlessness over their situation.

### **Accommodating the cost of food within a tight budget**

Another factor influencing eating habits was the cost of food. The perceived high cost of fruit and vegetables and diabetes-friendly products such as low-sugar products led participants to make decisions about which foodstuffs to purchase, and needs to be understood in the broad context of participants' limited incomes. As Nicole, a participant who took part in the Indigenous focus group, reflects:

*Mind you I'm not really motivated to eating a healthy diet... because it doesn't really go into... my budget.*

[Nicole; 50s; tablets; diagnosed 10 years]

Most participants reported that fruit and vegetables were very expensive, and they also identified meat as being expensive. Liz provides an account which highlights issues reported by most participants; she initially talks about her diet, which leads her to reflect on the affordability of meat:

*I try and eat more vegetables than meat, and I try and have fish as much as possible, mainly because realistically I can't afford the meat these days. If I have mince and I'm making a potato pie or something, I'll cook it up, I'll boil it up first, I mean, it doesn't smell very nice, but you boil it up first and then I put it in the sieve and run hot water through it to get all the fat and everything out, and that tends to help. Plus it gets all the preservatives out ... because it affects some people; it doesn't worry me.*

Later, Liz talks about shopping for fruit and vegetables:

*Fruit and veggies are difficult, because they are expensive, and the cheaper ones are normally... just about in a stage to put them in the bin, so that makes it a little bit difficult.*

[Liz; 60s; tablets; diagnosed four years]

Liz's observation of the poor quality of the cheaper produce is echoed by Marko, a participant whose account revealed high levels of stress and who reported being concerned about the impact of environmental factors on his health. Marko reflects on the high price of fish, and his comment reveals his perception that more affordable fish imported from Asian countries is of a lesser quality:

*Fish... you got to eat the fish. Fish is thirty, forty dollar a kilo... Overseas fish that you can't eat come from the slum down there in Vietnam or China; you know that fish is terrible to eat, you can't eat it. We bought it a few times, but you can't eat it; you got to buy the fish for thirty, forty dollar a kilo. Australian fish it's only what I can eat. [...]  
Australian products are ten times dearer than the Asian. The Asian countries, uh... sometimes they tell you in the television that it's unconsumptible [sic], you can't eat it...*

[Marko; 70s; tablets; diagnosed 10 years]

Participants also commonly reported that diabetes-friendly products such as low-sugar jams, low-fat margarines or wholemeal breads were more expensive than their less healthy counterparts. The perceived high price of these products was discussed among participants during the non-Indigenous focus group. Leah and Diane, both young mothers, talk about the impact of the cost of food on their family budget:

*Leah: yeah, you know that ... the butter with the low cholesterol, all that is just a couple of dollars extra.*

*Diane: yeah, I've noticed the margarine, you know... just the normal margarine... it's like you go from getting the cheapest for one to two or three dollars to getting the one... at maybe six dollars, and you sort of look at it and you go... I mean even bread now, because I've changed breads from... and I'm like, all right, I'll give it a try. You go from being*

*able to get like a one-dollar-thirty-bread to two dollars something, three dollars for bread, you're like... [laughs for emphasis]... you can't always, you can't always do it. 'Cause, I mean, on my... what I get for me and the kids, because [the children's father] is not always there, it goes towards, you know, the bills and everything like that, and what you've got left is what you've got to do the shopping with. And, like, I mean my daughter is still in nappies, so you buy nappies. It makes it harder to... usually you go around and you do the huge, quick... you get the quickest and the cheapest stuff you can, and that's not always the best stuff for the people who're going to be eating.*

[Leah; 30s; tablets; diagnosed eight years. Diane; 20s; tablets; diagnosed one year]

Diane's comments highlight the dilemma faced by many participants: choosing between the healthier, more expensive option and the less healthy, more affordable option. While some participants reported making an effort to buy the healthier option or not buying the food item at all if they felt it was outside of their price range, others admitted to buying the cheaper alternative, as Diane hinted in her comment. Similarly, Tony comments:

*I want to buy the diet jam, but it's twice as dear as the normal jam. Everything that is... that I'm supposed to... it's got a Heart Tick<sup>19</sup> on it and it's good for diabetes is dear. You know, you think, well, you know, you're on a bit of a budget so I'll just, you know, skip that; I'll buy the marmalade that I shouldn't have, because it's cheaper, you know.*

[Tony; 50s; tablets; diagnosed 10 years]

Participants' perception of the high cost of food in general and of diabetes-friendly food in particular needs to be understood in the context of their limited incomes, as Diane's and Tony's comments illustrated. References to the limitations to the shopping budget imposed by a limited income were common among participants. Cecil touches on this issue as he talks about his and Bridget's shopping habits:

*Because we've been on pensions, we just go and get the cheapest of the cheapest that we can. But, you know, like, some lean meat and stuff like that are really expensive. Like, she'll go and buy me a packet of diced pork and then you see the diced pork with this taken off and that taken off, and it's more... and we really can't afford it, can we?*

[Cecil; 50s; insulin; diagnosed five years]

Similarly, Gail and Joan, two Aboriginal participants who were interviewed together, discuss the impact of their limited budgets:

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<sup>19</sup> Tick of approval of the Heart Foundation of Australia which is displayed on packaging and represents a healthier choice within a food category.

Gail: *you've got to have your fresh fruit.*

Joan: *yeah, you've got to have fresh fruit. Time I pay all my bills... I have all my bills taken out of my pension; I've got twenty dollars left...*

Gail: *not much left; no.*

Joan: *... to buy.*

Interviewer: *so how do you make it go around?*

Gail: *you don't.*

Joan: *[...] money-wise I can't, but uh... kids always bring fruit, you know, and things like that... we find it very hard.*

[Gail; 70s; insulin; diagnosed 20 years. Joan, 70s; tablets; diagnosed five years]

Alison, a participant who came across as having given considerable thought to all the points she wanted to make during the interview, reflected on the financial impact of diabetes, and her articulate account summed up the issues faced by many participants. She talks about the cost of diabetes-friendly foods, which leads her to reflect on the challenges faced by those living on restricted incomes:

*Diabetic-friendly foods are quite expensive, you know. I know there's like, you know, there's a lot of things on the shelves, you know, you can... you can buy jams and specialty diabetic food, diabetic lollies and chocolate, but they're all significantly higher-priced than regular foods, so yes, they do. And even... even to purchase the healthier foods, whether you're diabetic or not, if you're on a low fixed income, it's very expensive, you know, I... at times sort of wonder if... you know, the powers that be, actually realise this, you know, living on a... living long term on a restricted income, it's very hard to buy the type of food... you know, like, I know they tell you eat lots of fruit, eat lots of salads, eat lots of vegetables... there are times when they're very expensive, different seasonal times of the year, and it's quite hard to financially manage it, you know...[...] I buy a lot of things in bulk, and I always go to a farmer's market, and I buy in bulk, and I cook a lot, and I freeze a lot of stuff. What I have to do is, I have to eat, because of financial restrictions, I have to eat what's in season, so, you know, if this week it's... if cauliflower is on special this week, we eat a lot of cauliflower, and if next week it's sweet corn, or peas, or whatever, that's what we eat.*

[Alison; 50s; tablets; diagnosed nine years]

In her account, Alison mentions strategies she has implemented to alleviate the impact of the cost of food on her limited income. These strategies demonstrate a set of organisational and practical skills, which can also be seen in Liz's account of her shopping routine. When asked where she does her grocery shopping, Liz, who lives with her husband Bill, also diabetic, replies:

*Over at Mirrabooka, either at Coles or Woolworths. And it's a matter of, these days, uh... because we just rely on the pension, it's all we've got, uh... I get the brochures out and because they're in the one shopping centre you can go from one to another. So I just get it out and write a list, and that's cheaper to buy it there, or something like that. And sometimes if there's things on special, like, you know, you buy two for the price of something... a neighbour, you know, I've got a friend down the road, you know, we'll share it, sort of thing. So, you know, instead of paying the ten dollars for the two, we pay five dollars each.*

[Liz; 60s; tablets; diagnosed four years]

Liz's comment demonstrates her budgeting skills and reveals the role her social networks play in ameliorating some of the financial constraints she and her husband Bill face.

### ***Eating and the family and social environment***

Eating is a social practice that often takes place in the company of others. Participants' narratives highlighted family and social circumstances which influenced their diet and eating patterns, and their accounts revealed that although some of these circumstances enabled participants to achieve a healthy diet, in the main they represented a further challenge to participants' self-control and will-power.

The majority of participants reported living with their partner and/or a family member, and their narratives indicated that their eating and cooking habits were influenced by the eating and cooking habits, and food preferences of those around them. The study sample included four married couples; this subsample allowed for an examination of the role each partner played in shopping and meal preparation, and the impact of each partner's role on their levels of self-efficacy around diet. Two couples reported that the wives played a major role in shopping and cooking, while the husbands limited their role to driving their wives to the shopping centre, and having limited, if any, input into cooking. Bill, who was interviewed separately from his wife Liz and who came across as having a very jovial personality, facetiously comments on their food shopping routine:

*I don't mind driving her [Liz] to the shopping, but I hate walking around, especially with Liz, she goes up that one [shop], and then back down that one. No thanks!*

Bill's passive role in meal preparation is brought to the fore when he makes the following comment about his diet:

*It's just virtually a normal diet, you know, we don't do anything fancy. I eat the same as Liz eats, cooks it all, and yeah, it's just a normal diet. [...] For breakfast I'll have a bowl of corn flakes, then for lunch I'll have a couple of sandwiches, and my main meal is tea-time. Could be a roast, could be anything she cooks, I'll just eat it.*

[Bill; 60s; tablets; diagnosed 10 years]

Liz reported having made some adjustments to their meals to accommodate Bill's food preferences, but, overall, Bill's and Liz's interviews revealed that both appeared to have found a balance in their diet; both reported good glycaemic control, and their narratives revealed a high level of self-efficacy.

A different experience was that reported by Michael and Rose, a couple of Indian-Burmese origin. Michael and Rose were also interviewed separately and they both reported that Rose was the person responsible for meal preparation. The narratives of their separate interviews revealed that they had very different levels of self-efficacy, and while Rose reported being strict about her diet routine and had implemented several changes to her diet, Michael reported finding it hard to adjust to the requirements of his dietary regime and give up his favourite foods. Rose, who reported cooking separate meals for her husband to accommodate his food preferences, talks about her diet, and her account shows her high level of self-control:

*I can handle not having things that don't agree with me, you know. I know it's bad for me, so I don't have it. I mean you're not going to die for it, you know. So I eat brown bread, brown rice, I drink soya milk. I uh... very seldom I'll drink sweet juices and that, only if my sugar level is going down. And I know when it's going down. So that's the only time I'll have it. I don't have it just because it's in the fridge there, no. I'm careful with my intake, you know.*

[Rose; 60s; insulin; diagnosed 20 years]

Rose's account is confirmed by her husband's observation of the different ways in which they deal with tempting foods when they go out socially:

*Yeah, she'll have sweetener; I'll have two sugars, please, you know. And cakes. There's cakes and everything's sweet, and I'll eat everything... She won't. That's the difference between her and me.*

[Michael; 60s; insulin; diagnosed 15 years]

The disparate ways in which they reported dealing with their self-management appeared to have become a source of tension between Rose and Michael. Rose brings up this issue when she reflects on why she prefers to go food shopping on her own:

*Rose: he'll just go for anything, you know, but me, I'm careful, just check the label, do this, do... but Michael no. And I said 'you've brought the wrong one', 'oh', he says, 'you're too bloody fussy, just eat the bloody...', I say no. So that's where all our arguments start. So I say 'I'm going to the shops', 'oh, can't you go after I come back from work?' So what he's trying to tell me is, he wants me to go with him. And I notice when we go together, we end up arguing because I'm checking everything, and he's screaming and yelling, and doesn't want to wait there, so I said no, that's it.*

*Interviewer: so you rather go...*

*Rose: by myself. No stress. OK, then I meet friends, and stop and talk for a little while, you know, makes me feel nice, and I come back home.*

[Rose; 60s; insulin; diagnosed 20 years]

Rose's account highlights her high stress levels, a dominant theme during her interview, and also reveals the emotional support she gets from meeting up with friends at the shopping centre.

Bridget and Cecil, one of the two couples who were interviewed together, had a different experience. During the interview, Bridget and Cecil came across as having a very close relationship, and they reported that they both cooked, praising each other's cooking skills. Despite the differences, their account presented some similarities to that of Rose and Michael's in so far as they both reported that Bridget was stricter with her diet, while Cecil reported struggling giving up favourite foods and, in general, reported a lower level of self-efficacy with regard to his self-management.

The remaining couple, Rhonda and Jim, were also interviewed together, and their narrative revealed an experience that was unique among study participants. The routine of their daily lives, including their food shopping and eating habits, were markedly affected by their financial difficulties, which were so severe that they reported being in the process of having an administrator appointed.

The analysis of other participants' experiences showed that when a couple's circumstances changed, cooking and eating habits may also change. The experiences reported by Martin and Tony highlighted this issue, and suggested that men might be



more susceptible because of their traditionally more limited role in meal preparation. Martin was born in India and he had been separated from his wife for five years when the interview took place. Martin reported having been diagnosed with depression and his account revealed a high level of social isolation. He lived in the company of his two dogs and his cat. When discussing his diet, Martin talked about the separation from his wife, who used to do most of the cooking, and he later admitted to hardly doing any cooking these days, adding:

*I find it pointless cooking for myself.*

[Martin; 60s; tablets; diagnosed 10 years]

Martin reported that he only cooked when one of his sons visited, ‘when you’ve got somebody else’. He also disclosed that he cooked more for his pets than for himself, admitting that he spent between a quarter and half of his income on them. The central place that his pets occupied in his life became evident when Martin referred to them as being ‘like family’ to him.

Tony, whose account revealed poor glycaemic control and limited knowledge about his dietary requirements, also reported changes to his diet since his wife had died several years earlier. Tony reflects:

*Well, when my wife was here, you know, she’d always make sure there was fruit on the table, on the bowl... and she made sure that we had fruit, uh... And I’ve sort of gone away from... from meats. I’m not a vegetarian, but I’d rather eat, uh... you know if I went out somewhere, I’d rather eat a vegetarian meal than, you know... And [...], my wife, we were always having barbecues on week-ends with the kids, and I was a lot bigger than what I am now, and I think it’s because of the fatty foods, you know, and the barbecue and that. Barbecues are a no-no, you know, uh... but I try and stay with a regime, you know, like an apple... I like apples... uh... and just try and stay away from meat and fatty foods, you know, if I can help it.*

Although Tony initially reported doing some basic cooking such as steaming or boiling vegetables, and preparing salads, later in the interview he admits:

*No, mainly my son cooks, I’m a hopeless cook. You know, I can boil veggies in the steamer and things like that, but he does that, and when my other son comes here as well, he lives with his girlfriend, but when he has, you know, a bit of a tiff, he comes as well. He’s a baker, so he brings nice bread home and... he’s the cook; he loves cooking. [...] I’m hopeless. I’m good at gardening and housework and that; that’s all.*

[Tony; 50s; tablets; diagnosed 10 years]

For both Martin and Tony, changes in family circumstances had a significant impact on their diets. In Martin's case, his separation from his wife had negatively impacted on his diet. Martin admitted to living on pre-cooked meals, and cited *Subway*® sandwiches as an example, explaining that he would typically eat half for lunch and the other half for dinner. Martin also talked about eating meat pies, acknowledging that they were not the ideal meal, and adding:

*You have to close your eyes and don't think about what's in it.*

[Martin; 60s; tablets; diagnosed 10 years]

In Tony's case, the impact had been more mixed, because, while on the one hand he reported eating fewer fatty foods and smaller portions, and having lost weight as a result, on the other hand, his account suggested that neither he nor his sons had a sound knowledge of the dietary requirements of a person with diabetes.

Other family circumstances also influenced participants' diet and hindered their attempts at achieving a healthy diet. The analysis of the accounts of two young mothers who took part in the non-Indigenous focus group suggested that having young children may pose a further challenge to will-power and self-control around diet. Diane, a single mother of two who reported struggling with her weight, reflects on how her diet has changed following her diagnosis, and her comment reveals how hard she finds to resist the sweet treats she includes in her children's lunchboxes:

*Very much so, like I used to eat whatever I liked before, and now I just have a banana and... yeah, that doesn't work, so I've been having to cut out a lot of the stuff that I used to eat. I don't eat a lot of sugar fatty foods, and I don't eat a lot of McDonald's® or eat any sugars, lollies... and it makes it hard because I've got children, I have those sorts of sugary... well, not sugary, but sort of sweet things for their lunchboxes.*

[Diane; 20s; tablets; diagnosed one year]

Leah, an Aboriginal participant who attended the non-Indigenous focus group, has three sons and reported a similar experience. Leah said that she could not stick to her diet, later adding:

*I'll eat what the boys eat, 'cause it's hard sometimes because your kids need sugar, your kids need fruit juice... so it makes it hard. So sometimes you go, 'oh, bugger, I'm just going to let go'.*

[Leah; 30s; tablets; diagnosed eight years]

Participants' narratives also revealed that many associated food and eating with family gatherings and special occasions, such as birthdays or Christmas, and the memories of good times spent in the company of their loved ones. Lorraine, a participant whose narrative was dominated by her frequent references to her many favourite foods, made particular mention of two dishes – 'sweet and sour' and 'cream of curry chicken' – which she was used to cooking whenever her sons and daughter visited, and that she associated with the enjoyment of having her family around her. She describes one such family gathering and explains the food choices she now feels obliged to make:

*Lorraine: ... when the kids come, I have all the things that they're used to, and I just put a little bit on my plate, I just sit on an hors d'oeuvre plate, a small plate, and I have that, just have a little bit. But I'm not allowed to add gravy. And that's my hardest bit... [facetious tone of voice] I was always the gravy one! So now I just have to put mint sauce on everything. And, you know, it's very hard!*

Interviewer: *is it getting any easier?*

*Lorraine: it is now, but at first, no, it wasn't, 'cause I was still putting it on my plate... oh, no, my sugar would go flying [chuckles] and I... and then I said to myself it's not worth it. And, of course, see, when the kids come I'll have a little bit of... a little bowl of sweet and sour with a little bit of rice. But I like the flavour of the juice, you see, and that's what I can't have 'cause I know it'll go to thirteen or fourteen or up to nineteen [blood sugar levels]. And I make cream of curry chicken... yum! Always home-made, everybody loves it and they always want it. And of course when the kids, when my daughter comes especially and my son... sweet and sour and curry chicken! But you know I can't eat all of that! [chuckles]. I've got to choose which one that I can have a little plate of. But I find that the cream of curry is the one that is worse than the sweet and sour, so... I just... I just got to give up. It's like giving up food for Lent [chuckles]!*

[Lorraine; 70s; tablets; diagnosed three years]

Lorraine, who reported finding it hard to adjust to the requirements of her diet at the best of times, experienced family gathering as further challenges to her will-power, which clouded the enjoyment of having her children around her.

One of the main challenges facing participants was how to adjust their dietary requirements during social outings, and many reported that social outings were the times when they were most likely to break their diets and indulge in a treat. Even participants whose accounts suggested a high level of self-efficacy found it

challenging to keep to their diets when going out socially. Sheryl comments on what she finds the hardest about keeping to the recommended diet:

*At one stage, you know, you go somewhere, and see everyone else is having a big chunk of cake or this or that, and you're like, 'can you cut that in half [laughs]?' I mean, you want to have a taste of it, but you don't want to, you know, overdo it. I think that is... those sort of things are hard. And you always get people who say 'oh, you know, that won't hurt you', when you think, well it does, it's going to make a difference, so... but, uh... yeah, I think, that's the worst part.*

[Sheryl; 60s; diet; diagnosed one year]

Liz had a similar experience. She reported that the hardest aspect of her diet was 'when you go out to people's places', and recalled an occasion when she had had a couple of glasses of *Coca-Cola*®, which resulted in raised glucose levels later that evening. Later in the interview, Liz reflects:

*So that sort of thing that you have to watch... but I mean, most of my friends do know that I am a diabetic, and they don't get upset if you don't eat the big piece of chocolate cake or something.*

[Liz; 60s; tablets; diagnosed four years]

Similarly to Sheryl, Liz mentions her friends' reaction to her saying no to certain foods. This was a common theme to many participants' narratives, and while some reported feeling comfortable with their choices regardless of other people's reactions or comments, many reported feeling upset and embarrassed. Alison provides an insight into this issue as she recalls a recent incident:

*I happened to be out recently with some friends, and they said, 'oh, let's just grab McDonald's®', 'I'm sorry, I can't do that, you know', 'Oh, why not?', 'Well, I can't eat that... you know, I don't eat that way'. And I sat there with everyone eating and I felt quite uncomfortable [laughs off], but uh... so it's inconvenient.*

[Alison; 50s; tablets; diagnosed nine years]

## **The challenges of exercising**

Participants' narratives showed that they viewed physical activity as an important component of diabetes self-management; however, their accounts revealed limited evidence of regular exercise, and suggested that participants regarded this aspect of their self-management as the most challenging to incorporate to their everyday routines.

Only a small proportion of participants reported having an exercise routine in place. Most of those who reported exercising regularly reported walking for exercise, and their routines varied with regard to length of time from half an hour to forty minutes, and with regard to frequency from several days a week to every day. Only two participants reported going to the swimming pool regularly as part of their exercise routine: Christine, a focus group participant in her sixties who has been diagnosed with diabetes for 20 years, reported going to the swimming pool and the gym every day for two hours, which raised expressions of admiration from the other participants; and Sheryl, an interview participant in her sixties on diet-only management, reported going to the pool with a friend about twice a week.

For most participants, physical activity was reduced to doing ‘normal’ daily tasks such as house chores or gardening, and several reported walking around the shops as their only source of exercise. Although a few participants’ narratives suggested that they regarded being generally ‘active’ as sufficient, most participants shared the understanding that exercise involved physical activity over and beyond the daily life routine, regardless of whether they reported exercising or not. In her account, Patricia, who reported having struggled with her weight for many years, explains why she is not currently exercising regularly, and in her comment she alludes to the difference between being ‘active’ and doing exercise:

*As I’m running around most of the time, I don’t [exercise], no, other than racing around the place. I’m not one for sitting around, I’m always doing something. I might be sitting around, but I’m doing something at the same time. But actually going out and doing physical exercise, no.*

[Patricia; 60s; insulin; diagnosed six years]

In general, participants’ narratives around exercise were framed for the perspective of the challenges and barriers involved, and although there were a few references to the positive impact of exercising, most accounts suggested that participants perceived exercise as a ‘duty’ to be performed rather than as a source of enjoyment. Unsurprisingly, the main themes arising from the analysis of participants’ accounts of physical activity were perceived barriers to exercising: lack of motivation; existence of co-morbidities and mobility issues; cost; and neighbourhood safety concerns.

## **Motivation to exercise**

The analysis of participants' narratives showed that motivation was essential to maintaining an exercise routine, and this was reflected in the words participants used to describe their experience. For example, participants talked about 'getting the momentum to do it', 'feeling like you are up to it', or 'being motivated'; and those who managed to make themselves 'get up and go' reported having an exercise routine. For a limited few, exercising appeared to come easily and did not require much will-power, while for others the motivation to exercise was driven by a specific goal, such as the need to lose weight for an upcoming knee replacement operation, or complying with the requirements of a drug trial.

For participants who reported not having any exercise routine in place, however, physical activity was experienced as an unfulfilled duty. Liz's response when asked about her self-management routine sums up the attitudes of many participants:

*Basically it's your meals, and what you eat, and have your tablets, and I have mine morning and night, so... I should do more exercise; I know that [emphasis].*

[Liz; 60s; tablets; diagnosed four years]

Liz's response highlights her understanding of the three 'pillars' of diabetes self-management: diet, medication and physical activity; and her inflection when she mentions exercise conveys this sense of 'duty' which permeated participants' narratives around physical activity, and is illustrated by participants' use of phrases such as: 'I should do more', 'I don't have a choice' or 'I have to'.

Anne, a participant who took part in the non-Indigenous focus group, commented on her perception of why people lack the motivation to exercise:

*But I think for a lot of us it's like, right, I'll do that walk around the park every day. Oh, no, it looks like it's going to rain today. Oh, no, it's going to be 40 [degrees] today, it's going to be too hot. And I think if I had a friend I would be more inclined to do more exercise than what I do. And yes, I get told and told that as a diabetic you've got to do exercise, go for that longer walk, do this, do that... but it's getting out to do it.*

[Anne; 50s; insulin; diagnosed 10 years]

Anne's comment is revealing for several reasons: firstly, Anne uses the pronoun 'us' to indicate that she perceives the issue of lack of motivation to affect everybody in

similar circumstances, not just her, thus diffusing her own agency. Secondly, Anne refers to weather conditions as hindering people's exercise routines, and her account suggests that she perceives these as excuses masking a general lack of motivation. Incidentally, weather conditions were indeed mentioned by several participants as barriers to exercise. Liz, for example, commented:

*There's no way I could walk in the heat.*

[Liz; 60s; tablets; diagnosed four years]

Lastly, Anne's final comment highlights how she perceives the self-management messages on exercise as a set of directives – 'do this, do that' – which do not address what she perceives to be the main barrier to physical activity: the lack of motivation.

Dot's account sums up many participants' attitudes towards physical activity as part of the management of their disease. Dot's narrative revealed a high level of self-efficacy with regard to most aspects of her self-management, and she appeared to have found a routine in her life that worked well for her. However, she admitted to not doing what she 'should' with regard to exercise. When asked what she thought was stopping her, Dot replies, chuckling:

*What's stops me? Well, it's in my head, but never gets to my feet, to be honest. [...] I don't know why; I don't know. I've said time and time again, it's just something that doesn't seem to, you know, as far as my diabetes is concerned, I think that's my biggest problem, it's the exercises.*

Later in the interview, Dot reflects:

*I think I'd go better if I was in a group than having to do... I think when you've got to do something on your own, you're not motivated enough to do it, but I think if I was in a group, that's... that's totally different. I would participate, but being on my own, I'm not motivated enough.*

[Dot; 70s; insulin; diagnosed 35 years]

Dot's comment reveals her belief that exercising in a group setting would help her overcome her lack of motivation, a view that echoes Anne's, and which was shared by many participants. Peter, a participant who reported struggling with his weight, had recently started walking with his wife in the evenings and was keen to find out about exercise groups in his local community. His comment highlights what he perceives as a positive aspect of exercising in a group setting:

*It's better to be involved with other people as well who've got the same problem. [...] Support groups where you can go and exercise with them, with other people, walk and talk. It sort of helps when you're with someone who's suffering from the same problems.*

[Peter; 50s; tablets; diagnosed seven years]

## **Co-morbidities and mobility issues**

Participants' experience of physical activity as part of their self-management needs to be understood in the context of their reported health status and my observations of their weight and mobility issues. As discussed elsewhere (see Chapter 4), most study participants reported having other diagnosed health conditions, including CVD, arthritis, asthma, cancer and depression. During the conduct of the focus groups and interviews, many participants reported the existence of health conditions while discussing physical activity; and they cited heart conditions, strokes, asthma, back injuries, knee and hip problems, arthritis, and balance and weight issues as barriers to exercise. My observations were consistent with participants' reports of their co-morbidities. I observed that some participants walked around with difficulty, and some required walking aids, such as walking sticks or frames. I also observed that most participants were overweight, which might have aggravated their reported back and joint problems. Finally, I observed that some participants presented laboured breathing – manifested through wheezing and coughing – and had to stop frequently during the conversation to catch up their breath.

Lorraine reported having balance problems and using a walking frame; and during the interview, I observed that she was overweight and moved around with extreme difficulty. Lorraine, who also reported having recently been diagnosed with angina, talked about the physical effort involved in going to the shops, and her account provides an insight into the impact of her multiple conditions on her mobility and quality of life generally:

*When I get to the shop I might have to sit down and, like, breathe a little bit, get my breath a bit, 'cause that's the asthma, which isn't very bad, I just get an attack now and then, it's not a thing that irritates me, you know. If I get a cold, well then, you know, you're going to get asthma, but other than that, it's just that I get a little bit breathless sometimes, that's all, and I've just got to sit. 'Cause my legs ache, but that's because of the brittle bones and the arthritis in the knee. And I've had a hip replacement done. Hmm... and I know I'm exhausted when I get back from the shop.*

[Lorraine; 70s; tablets; diagnosed three years]



Bridget and Cecil both reported that their health problems limited their ability to exercise. At the beginning of the interview, Cecil reported that he had been suffering from intense pain in his shoulder, the cause of which was being investigated. Cecil and Bridget reflect on his physical inactivity:

Cecil: *I really don't do much, do I? Sometimes I go out, like I'll drive out to the video store, walk around and look at things. If I go to the library, I walk around or, you know... and that's the only time I get... I get a bit of exercise.*

Interviewer: *has your doctor recommended that you do some exercise?*

Cecil: *oh, he has, but I find...*

Bridget: *while he's in pain...*

Cecil: *while I'm in pain, I just don't want to do anything but sleep and you know, control the pain.*

Later in the interview, Bridget talks about how active she is despite the fact that she walks with a walking stick, which leads her to disclose the serious health problems she has had in the last two years:

Bridget: *I'm really active, aren't I, really?*

Cecil: *yeah.*

Bridget: *a bit limited because I'm on a walking stick, but I'm still pretty active. I mean, I jump on the trampoline with my grandkids and we jump together. They hold my hand, so I can jump with them. When it's not cold, I go down the park at... I like walking along the park.*

Interviewer: *which park do you go to?*

Bridget: *just down here there's one, not far down that way. But he worries that I'll collapse or something, so I don't go too long or I take my mobile in case he gets worried. But, uh... 'cause I've been so sick, he gets a bit scared, don't you?*

Cecil: *uh-huh.*

Interviewer: *what's happened?*

Cecil: *I do worry about her...*

Bridget: *uh... 'cause I suffer anaphylactic shock; it just comes on. One minute I'm fine, the next minute I'm in an ambulance and I'm gone.*

Cecil: *yeah.*

Bridget: *I've been in two comas in the last two years.*

[Cecil; 50s; insulin; diagnosed five years. Bridget; 40s; insulin; diagnosed seven years]

Similarly, Michael, who reported recently having had a shunt placed in his brain to alleviate a build-up of fluid, talks about the impact of the deterioration of his physical condition on his ability to exercise:

*I used to go to the gym every morning, used to walk every morning. I can't do those things anymore because I feel giddiness. I keep falling off, falling down all the time.*

Later in the interview, he adds, with a note of sadness and frustration in his voice:

*I can't walk to the shops anymore.*

[Michael; 60s; insulin; diagnosed 15 years]

Injuries and medical conditions were also common among participants who reported exercising regularly, and placed limitations on the types of exercise in which they could engage. Sheryl was one of only two participants who reported going to the swimming pool regularly; when asked if she swims, Sheryl explains:

*No, well, I can't swim, you know, I just exercise. [...] We walk, and if I can swim, I do, depends on my spine. I've got a spinal problem as well. So, uh... I do a bit of swimming, but mostly walk, and exercise, that sort of thing, yeah.*

With regard to walking, she comments:

*'Cause before I used to walk a lot of the time, you know. I brought my old buggy and off I'd go with the dog and do the shopping and things like that, but I just can't do it anymore. And walk around the oval two or three times a week, or most days, actually; but I had to give all that up as well.*

[Sheryl; 60s; diet; diagnosed one year]

Mandy, who also reported exercising regularly, commented that she had arthritis in her knee, and walking aggravated it, adding:

*It's not a problem sort of getting up and going, it's just that after I've been walking for about five minutes, yeah, it starts to hurt.*

[Mandy; 50s; tablets; diagnosed two years]

A similar experience was that of Peter, who was diagnosed with diabetes after having a heart attack. Peter had recently begun walking regularly, and he explains how a back injury stops him from doing other types of exercise:

Peter: *well, I can't do much because my back doesn't bend, so it's hard to sit on a bike and pedal, because I can't bend forward and I can't get one with high handles.*

Interviewer: *so you walk mainly?*

Peter: *yeah, I walk around the block. At the moment I'm doing about a kilometre a night. I'll ease into that and then I'll start getting around the bigger block.*

[Peter; 50s; tablets; diagnosed seven years]

Participants' narratives also revealed that many were affected by diabetes-specific quality of life issues, such as general fatigue and sore or 'burning' feet – a symptom of peripheral neuropathy associated with diabetes. During the Indigenous focus group, the following exchange took place among participants when discussing their doctors' recommendations with regard to exercise:

Renee: *it's good for you...*

Robert: *don't overdo it.*

Renee: *but don't overdo it, only do what you can, like walk, a bit of walking, you know, around the garden and things, you know, just a bit of walking around the house, not too far 'cause sometimes, when you're a diabetic, you find it's sore underneath the...*

Frances: *under the feet, that's where the sugar is, you see...*

[Renee; 50s; dialysis; diagnosed 20 years. Robert; 60s; tablets; diagnosed five years. Frances; 70s; tablets; diagnosed 40 years]

This exchange reveals participants' health beliefs and highlights the issue of finding a balance between the level of exercise recommended generally, and the level of exercise which can realistically be achieved based on the individual's personal circumstances. The exchange also brings up the issue of peripheral neuropathy, to which Paul also refers when he explains why he has reduced his walking:

*Well, I started walking to the shops and then I hopped to the car, because by the time I get back, you know, the bottom of my feet are hurting... my toes... When I stand in the bath, in the shower, and close my eyes, I could... I fall over. I don't, but...*

[Paul; 80s; diet; diagnosed 18 months]

Gail, an Aboriginal participant who took part in a joint interview, provided one of the rare positive accounts around exercise. Gail reported that her family had bought her a *Wii™ Sports* game and she credited the game for giving her 'a second lease of life'. When discussing her lack of energy, she reflects:

*Yes, I am tired... but since playing these games, I've got a second lease of life. I don't feel any... I don't feel any pain in my body; my body's never felt so good. I've only been doing it for about three weeks.*

Later, Gail adds:

*The exercise is taking the pain out of me, but I still haven't got the energy... I'd like the energy that I can walk around the block.*

[Gail; 70s; insulin; diagnosed 20 years]

Reports of lack of energy were common among participants, and even if participants did not specifically cited this as a barrier to exercise, fatigue coloured most participants' experience of living with diabetes, as will be discussed in Chapter 8.

### **Cost as a barrier to exercise**

Financial considerations were also perceived as a barrier to exercise. Participants viewed gymnasiums and swimming pools as desirable but largely inaccessible due to the cost of memberships and entry fees. Anne, a participant who took part in the non-Indigenous focus group, reported struggling with her weight; while discussing physical activity, she comments on what is stopping her from doing more exercise:

*I'd like to try the gym, but I just don't have the money, so that's a stopping point. You know, the slice of everything else, and, you know, health funds and everything, going to a gymnasium... I had a heart attack in August, and I'd been going to the physio [...]. I think I went twice a week for six weeks, and I really saw the benefit [...]. I'd love to continue, but money stops me from doing that, so...*

[Anne; 50s; insulin; diagnosed 10 years]

Anne's comment suggests a feeling of frustration at not being able to afford the gym, which is aggravated by her own experience of how beneficial exercise can be. Similarly, Liz, who reported walking around the shopping centre as her only regular exercise, comments:

*I would go swimming more, you know, if we kind of could get there a bit more often, but... I mean realistically finances play a big part in how we live, because, you know, it's extremely hard. You live virtually on one pay, because the rest goes on rent, so that makes it difficult.*

[Liz; 60s; tablets; diagnosed four years]

The cost of petrol was another financial consideration reported by participants as a barrier to exercise. Sheryl, a participant who came across as being highly motivated, comments on why she does not go to the pool more often:

*I'd go every day, but, by the time you put petrol in your car, you pay to go in the pool, it sort of adds up, you know, yeah...*

[Sheryl; 60s; diet; diagnosed one year]

Similarly, Alison, who during the interview made frequent and detailed references to the ways in which her and her husband's low incomes impacted on the way they lived, illuminates this point further:

*I really need to do some swimming for my... that would be really good for my health, for my back and my diabetes, but... things like, you know, even using a car, when you're on a very low income, you often can't afford to keep a car running for more than the absolute basics, you know... it's fees to join clubs or support groups, you know, they usually require a fee or a weekly fee.*

[Alison; 50s; tablets; diagnosed nine years]

Alison's reference to using the car for the 'absolute basics' points to the need to prioritise living expenses in the context of limited incomes. This issue was echoed by Marko, a participant whose narrative suggested a high level of stress and social isolation. When asked whether his doctor had recommended exercising, Marko reflects on the costs involved and refers to the need to cover 'the essential things' first, given his limited income:

*It would be good, yeah, but, uh... I can't afford it... Every session is six, six dollars, if you go twice a week... I get only two hundred dollars a week, with all the expenses, they go through the roof all those things [...] I get ten thousand dollars a year, and I've got to pay everything with my ten thousand dollars. I can't afford to go to the exercises, or anything, just the essential things, buy food and pay the bills, electricity and all insurances. And money doesn't go any way, what a pensioner gets today.*

Throughout the interview, Marko frequently mentioned his need to exercise; in the following comment, he articulates his beliefs around the health benefits of joining exercise programs, which help explain his frustration at his inability to afford them:

*They say you go for a walk, but many people they can't walk, you know... You can walk slow, but slow walking doesn't do that much. When I go to walk the dog, I can't walk with a fast speed, you know, fast speed to get the heart going. And when you get those exercises, and continue to do*

*that once or twice a week, you get... the system starts to... build yourself up, and things start to get better, you know. [...] Just sit here and go for a little walk; that is not really the thing...*

[Marko; 70s; tablets; diagnosed 10 years]

The mention of cost as a barrier to exercise generally elicited emotive responses, revealing feelings of frustration, and providing an insight into participants' own sense of disadvantage.

### **Neighbourhood safety concerns**

As previously discussed, walking was the type of exercise most commonly reported by participants. While this form of exercise has the advantages of being more easily integrated into a daily routine, and not having a cost associated with it, some participants' accounts unveiled concerns about neighbourhood safety which acted as a barrier to walking.

Patricia, who reported struggling with her weight and having lymphoedema in both legs, admitted that she had a busy schedule and lacked time to exercise; asked whether she goes for walks, Patricia promptly replies:

*Outside? No. 'Cause you don't know what's around. Two or three houses on the other side is one of the biggest drug houses in Perth.*

[Patricia; 60s; insulin; diagnosed six years]

A similar account was provided by Liz, who reported that she did not have an exercise routine in place, and admitted that she would not want to walk around in the early hours of the morning. When asked why, Liz tentatively responds:

*Well... I suppose the safety issues. I mean you just don't know what's going on out there. It's different to when we were kids.*

Liz elaborates on her answer, and her comment reveals how the media rather than her own experience, has shaped her perception:

*Well, this is quite a good area... I mean the other day there was something in the paper about a woman that had been raped in this area. I heard it in the news or the paper. You think, gee, you thought you were safe, but maybe you're not.*

[Liz; 60s; tablets; diagnosed four years]

Similarly, Alison talks about her exercise routine, which leads her to discuss her safety concerns:

*Alison: well, I go for a walk for about forty minutes a day, just around the suburb, just... I kind of vary it, I don't like to follow the same route. They tell you it's not safe, but... I've got several routes worked out that I walk, and it usually takes about forty minutes. I try to do it at least five times a week.*

*Interviewer: is that in the morning?*

*Alison: yes, usually in the morning, yes. Not always, but usually, yes.*

*Interviewer: tell me a little bit more about... you mentioned that people tell you it's not safe to walk.*

*Alison: no, not in this area, no. It's uh... well, I must admit, in general, in Perth I feel... I feel less safe in Perth than I've ever done. Uh... you know, I've lived here since 1964 and in the last four or five years, I do feel unsafe. I would never go out alone in the evening, unless I was in the car with the doors locked. Uh... you know, I wouldn't feel comfortable going into the city. It may all be hype, I don't know, but we're always seeing, you know, in the media, that there have been people, you know, bashed and robbed, and uh... it's a bit scary.*

[Alison; 50s; tablets; diagnosed nine years]

Alison concedes that neighbourhood safety concerns might be a 'hype' created by the media. In contrast with Patricia's and Liz's accounts, these concerns do not stop Alison from exercising; however, they do shape the way in which she conducts herself and the time at which she chooses to exercise.

## **The experience of clinical self-management**

Diabetes self-management includes not only lifestyle but also clinical components. In this section, I present the results on participants' experiences of the clinical self-management of their disease including their experiences of taking tablets, injecting insulin, and performing self-monitoring of blood glucose.

### ***The routine of taking tablets***

Most participants reported taking tablets for the clinical self-management of their diabetes; however, reports of number of tablets and frequency ranged between one tablet once a day – typically taken in the morning – and several tablets three times a day. Participants' accounts revealed that they experienced this component of their self-management as an everyday routine. Furthermore, because diabetes medication

is routinely prescribed alongside medications to control hypertension and hypercholesterolemia, the majority of participants experienced taking their diabetes medication as part of the routine of taking multiple tablets, which some had experienced for many years.

The most common issue reported by participants with regard to their diabetes medication was forgetting to take it, although, overall, this did not appear to be a major concern. Some participants reported forgetting to take their tablets occasionally, but in most cases they reported experiencing no side-effects as a result. Mandy, who had been on diabetes medication for two years and reported good glycaemic control, provided an account which illustrates this experience. When asked how she feels about having to take her tablets daily, Mandy responds:

*Yeah, they're easy, except for the lunch one, sometimes I forget, if I'm not here. 'Cause I carry one with me just in case, and sometimes I forget to take it, I forget it's in my pocket [laughs].*

[Mandy; 50s; tablets; diagnosed two years]

Similarly, Bill, who also reported good glycaemic control, comments:

*Oh, on occasion I might forget to take one at night, but very rare, because they always sit on the table.*

[Bill; 60s; tablets; diagnosed 10 years]

In contrast, Frances, an Aboriginal participant who took part in a joint interview and who reported having very high BSLs, provided a significantly different account. Frances talks about her daily self-management routine, and describes the symptoms she experiences when she forgets to take her medication:

*Frances: first of all I take my tablets in the morning, but sometimes I forget.*

*Interviewer: yeah, how is that?*

*Frances: well, I just forget, I don't take it... being naughty! [chuckles]*

*Interviewer: yeah. So what happens when you forget?*

*Frances: then at eleven o'clock, you know, I start getting a headache and I start feeling sick.*

[Frances; 70s; tablets; diagnosed 40 years]



Frances' comment needs to be understood in the context of her very poor glycaemic control, which became apparent during the course of the interview, and was confirmed by Frances' report that her doctor wanted her to go on insulin.

Participants referred to aids and prompts which helped them to remember to take their tablets. Organising the tablets in plastic dispensers containing the necessary dosage for the week or leaving the medications in full view on the kitchen top were some of the strategies reported. Bridget and Cecil, who reported being on hypoglycaemic tablets and insulin, reported having recently purchased two medication dispensers with an in-built alarm for Cecil's use. The following exchange reveals Cecil's 'positive' experience of forgetting to take his tablets, which might explain his previously ambivalent attitude towards his medication:

*Cecil: the weird thing is, with my eyes, I'll take my tablets, you know, on a regular basis, and then to watch the TV it's all blurry, so I have to use my glasses. But if I forget to take my tablets for three to four days, I have to take my glasses off to watch TV because it's all clear. Right now you two are all blurry. But, you know, I said this to my doctor, to the eye specialist, and she says, 'oh, because when you don't take your tablets, the blood sugar level goes up high, and your eyesight, you know, magnifies it'. And I went, 'so that's a good thing, isn't it?' [chuckles] She went, 'no, it's not' [laughs].*

*Bridget: he has extremely high readings [...]*

*Cecil: yeah, because I've been... misusing my uh... medication. I sort of take it when I feel like it. Now...*

*Interviewer: your medication?*

*Cecil: yeah, but now it's on a regular basis.*

*Interviewer: and when you were misusing it, why do you think...?*

*Cecil: laziness. It was just... I was too damn lazy to get up and do it.*

*Bridget: I even bought him this [points to a medication dispenser on the table] and that's got an alarm on it. [...]*

*Cecil: every morning...*

*Bridget: every morning at 9 o'clock the alarm goes off.*

*Cecil: so, while I have to walk... you have to walk and turn it off [...] and I think, oh, I've got to turn it off, I might as well take it, I'm here [laughs].*

*Bridget: so I bought him one for the morning and one for the night, because he just wouldn't take his medication so...*

[Cecil; 50s; insulin; diagnosed five years. Bridget; 40s; insulin; diagnosed seven years]

The exchange highlights Bridget's active role in ensuring that Cecil takes his tablets regularly. A similar experience was reported by the couple formed by Liz and Bill, as Liz's account of her medication routine reveals:

*I put them in the plastic box. I do mine and I do Bill's up. And I put them in the little box every week, and I find that's easier; and it's also easier to know when you're running out of them, the tablets.*

[Liz; 60s; tablets; diagnosed four years]

Liz's role with regard to medication adherence is confirmed by Bill's account:

*Yeah, we've got them in those boxes, not the sealed ones, but Liz dishes them out every morning. I can't do it, and she just sits there and does it. I just take the ones in the morning, the ones at night, that's it.*

[Bill; 60s; tablets; diagnosed 10 years]

All Derbarl Yerrigan clients interviewed reported having their medication delivered in a Webster-pak<sup>®20</sup>, and they referred to this aid as an important part of their self-management. Doris, a participant in the Indigenous focus group, sums up:

*The best thing that happened was when the Webster paks<sup>®</sup> came in.*

[Doris; 60s; tablets; diagnosed 11 years]

The issue of the cost involved in having the medication sorted in Webster paks<sup>®</sup> was not raised among Derbarl Yerrigan clients, as they had access to this service free-of-charge. It was, however, raised by Rhonda and Jim. Rhonda reported having had a stroke, and mentioned that a *Silver Chain*<sup>21</sup> worker came every week-day in the morning to help her with her medication, while at the week-end she received telephone prompts. Rhonda and Jim disclosed that their household was in financial turmoil, which led them to discuss the issue of the cost of their medication:

*Jim: this is one of the points I was going to raise, but... in this household financial budgeting is chaotic... for various reasons, which, at times, limits the amount of food... shopping we can do, which if we've got to do medication... [...]*

*Rhonda: medications can get a bit expensive.*

*Interviewer: right. Because each of you, you've got several medications, right?*

*Jim: yeah. [...]*

*Interviewer: and how much are you paying for each of the prescriptions?*

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<sup>20</sup> Sealed multi-dose medication dispenser prepared by pharmacists.

<sup>21</sup> Not-for-profit organisation providing community nursing care.

*Jim: well, the majority of Rhonda's and my medications is five fifty, but on top of that, for our Webster care packs, there's an additional fee the pharmacist charges, five dollars a week.*

[Rhonda; 60s; tablets; diagnosed three years. Jim; 60s; tablets; diagnosed eight years]

Despite the potential benefits of Webster-paks®, Jim and Rhonda's comments reveal the implications of paying a weekly fee of \$10, a substantial additional cost given their precarious financial circumstances.

The cost of medications was not raised by many participants as being of concern, and it was not perceived as a barrier to self-management. All participants reported being in possession of a concession health card, and thus the cost of each prescription was reported to be between \$5.30 and \$5.50. Incidentally, two participants commented on the fact that the cost of medications had been a major issue for them when they were in employment. Patricia, who retired on health grounds due to the lymphoedema she suffers in both legs, reported being on several medications as well as insulin; she recalls what she used to pay for her medications when she was working:

*I was paying fifty dollars for several months' insulin, and because I'm on such a low dosage, it lasts a long time, but that's a lot of money to come out of your wages, plus other medication as well. I was paying around seventy, eighty dollars a fortnight on medications, so I can understand how people are really suffering with it.*

[Patricia; 60s; insulin; diagnosed six years]

Tony, who had been on a disability pension for only a few months when the interview took place, reported a similar experience. Tony recalls how costly his medications had been when he was in employment:

*When the last by-pass operation, one of the diabetes doctors came and, I was taking two of the Glyades<sup>22</sup>, you know, one morning, and he came and he said, 'look, you should up it and take the Diaformin<sup>23</sup>'. Now, I pay a hundred and fifty dollars on tablets, and you're giving me more tablets, oh, man, you know... And I was only then working for the Shire, you know, not much money...*

He later adds:

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<sup>22</sup> Diabetes medication. Active ingredient: glicazide.

<sup>23</sup> Diabetes medication. Active ingredient: metformin hydrochloride.

*All these tablets are very, very dear, you know, so... yeah, it was very, very hard for me. Uh... it's a lot easier now that it's five dollars thirty a script, so I feel free to go down and, you know...*

[Tony, 50s; tablets; diagnosed 10 years]

Tony's comment is revealing, because when he mentions that now he 'feels free' to go on whatever medication he is prescribed for his medical conditions, he seems to be implying that before cost was a factor that might have stopped him from incorporating additional drugs to his medication regimen that might have been beneficial to him.

Although most participants seemed to have adjusted to their daily medication routine, some participants reported feeling a sense of frustration at having to take tablets, and they tended to be those who reported having several diagnosed medical conditions and being on multiple medications. This was the case of Marko, who reported taking only one tablet for the management of his diabetes, but experienced this as an added burden to his long list of medications. During the interview, Marko mentioned several times that he did not like taking tablets, even though he knew he had to take them. He reflects on his medication regimen:

*All those medications... it's just medication, you know, it doesn't really do that much to you...*

Later in the interview, Marko's comments about the side-effects of the medication he takes for his depression provide an insight into his quality of life and illuminate his ambivalent attitude towards medications in general:

Marko: *they make you dizzy, and then you can't drive the car, you can't go out, you feel... you have to sit down and fall asleep.*

Interviewer: *'cause they've got side-effects?*

Marko: *yeah, they've got side-effects, you can't really take them. See, I take one, I take a quarter and still feel... I take it at night and still all day I sit down and fall asleep straight away, only a quarter... Make you stupid. It does relax you, but you can't sleep all day every day, can you? You've got to go somewhere, and you feel funny in the head sometimes, can't drive the car... and then if you walk, you fall over very easy too. At my age... it's not the medication... But you've got to use it, you know...*

[Marko; 70s; tablets; diagnosed 10 years]

Similarly, Anne's account reveals how she experiences being on multiple medications. Anne reflects on her medication regimen, and her comment highlights

the complexity of the management of her multiple conditions, and her understanding of the interactions between the different medications she takes:

*I think if you take more than one thing... I'm on Warfarin<sup>24</sup>. I mean, I'm taking 17 tablets a day, four injections, two puffers<sup>25</sup> and... it can all really get on top of you. You get an imbalance, like I'm on antibiotics, that's to stop it sending my Warfarin through the roof... And it just gets a little bit on top of you sometimes...*

[Anne; 50s; insulin; diagnosed 10 years]

In her comment, Anne refers to her insulin regimen, a component of diabetes self-management which participants experienced as having a much greater impact on their daily routines.

### ***The experience of injecting insulin***

A total of 11 study participants – five Indigenous and six non-Indigenous – reported injecting insulin as part of their clinical management of diabetes, and reports of frequency varied from once to four times daily. Three participants reported being on an insulin-only regimen, while the remaining eight reported also taking tablets as part of their clinical self-management. One participant, Renee, an Aboriginal woman in her fifties who took part in the Indigenous focus group, reported being on dialysis for the management of diabetes-related renal failure. Moreover, Diane, a young mother of two who took part in the non-Indigenous focus group, reported having been on insulin during her second pregnancy for the management of her gestational diabetes.

Participants who reported being on insulin revealed their intense dislike of needles, and their initial fear and shock at having to inject themselves. Patricia, who reported having been placed on insulin shortly after her diagnosis, recalls her first experience:

*It can be very frightening, when you first get it, 'cause you have all these ideas of... well... I went in there and I said to them 'you're not putting me on insulin 'cause I'm not going to give myself a needle'. The thought of holding a needle in my hand absolutely frightened me... And the nurse educator looked at me and said 'it's not a needle as you go and have a needle at the doctor's, it's like a pen'. And when she showed me, she did it, I was fine. But it's not knowing that makes it frightening.*

[Patricia; 60s; insulin; diagnosed six years]

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<sup>24</sup> Anticoagulant used to prevent heart attacks, strokes and blood clots.

<sup>25</sup> Asthma medication inhaler.

In her comments, Patricia's choice of words – 'frightened', 'frightening', 'scared' – convey her deep feeling of fear. Rose's account of the first time she injected echoes this negative sentiment. Her narrative revealed a high level of self-control with regard to her diet, and she came across during the interview as wanting to present herself as coping well; however, when Rose is asked how she feels about injecting, she spontaneously replies:

*Oh, it was hell for me the first time!*

[Rose; 60s; insulin; diagnosed 20 years]

Rose did not elaborate on her answer and promptly changed subject after this comment, suggesting that she did not feel comfortable discussing this aspect of her self-management, perhaps because it contradicted the image she portrayed of someone who had a high level of self-control and self-efficacy. Rose's husband Michael, who was interviewed separately, reported having 'no problem' with his insulin regimen, and claimed that Rose was the one who had issues with it. Michael starts discussing how he feels about his own injecting routine, and immediately refers to his wife's:

*Yeah, no problem. The missus has a problem. She's on the same medication as me, and she pokes herself and I look at her, I look at the time, five minutes, ten minutes, fifteen minutes, she's still going, slowly, slowly [sounds amused]. I just open my stuff, open, bang, press it in, that's it. Within one minute I'm all finished.*

[Michael; 60s; insulin; diagnosed 15 years]

Michael's comment is revealing, as he appears to be mocking his wife's difficult time. This reaction is consistent with their narratives, as Michael's and Rose's accounts suggested that they had a complex relationship, which appeared to hinder rather than help either of them with the demands of their self-management.

Cecil, who admitted to having neglected to take his medication regularly in the past, also revealed negative feelings about needles and injecting. The following exchange takes place after Bridget reveals that Cecil has recently been placed on insulin and he will not inject himself:

*Cecil: I just hate needles; I don't like needles in me. But every time she does it, even these tiny little things, they still hurt. I try and do it and I get this far and I freeze, I just can't move.*

*Bridget: I do it every night.*

Cecil: *I'll never be able to inject myself.*

Bridget: *I do my own and then I go out and do his.*

[Bridget; 40s; insulin; diagnosed seven years. Cecil; 50s; insulin; diagnosed five years]

This exchange reveals how Cecil depends on his wife for his clinical management, and highlights Bridget's higher level of self-efficacy. Later in the interview, Cecil elaborates on his fear of needles, explaining the difference between the glucometre<sup>26</sup> needles and the insulin needles:

*It's funny though, because I poke myself with that machine [points to the glucometre] and the needle goes in, and that hurts a lot more than my insulin. But I think it's just the fear of a hypodermic syringe going in...*

[Cecil; 50s; insulin; diagnosed five years]

Insulin-dependent participants – especially those who reported injecting several times a day – reported having to plan their lives around 'the needles', particularly when going out. Anne describes her daily self-management routine, and her account reveals how she experiences the restrictions injecting imposes on her lifestyle:

*The needles, putting the needles four times a day, working around where you're going, and where can I go, if you're going out for lunch, where can you go to put the needle in before you start eating. [...] And then before you go to bed is fine, but if you have to go out anywhere, you know, even if it's to your mother's... before dinner... where do we go? If you're out in a restaurant, where is the toilet? You know, hoping that nobody comes in... like a heroin addict or something, you know...*

[Anne; 50s; insulin; diagnosed 10 years]

Anne's comment highlights her perception of the stigma associated with needles and injecting, a common theme among participants. Patricia echoes this sentiment when she comments on her own routine:

Patricia: *the biggest problem I have when food is concerned is if I go somewhere, is having my insulin. That is a big problem.*

Interviewer: *how often do you have to inject?*

Patricia: *four times a day. But very low amounts, so... especially lunch-time. But, yeah, that's my biggest problem, and that I really get upset about at times.*

Interviewer: *tell me a bit more about that.*

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<sup>26</sup> Blood glucose monitoring device.

Patricia: *well, like, if you go shopping and you decide that you have some lunch out, you've got to go into the toilets to have it, and sometimes the toilets aren't exactly clean, and that really upsets me. And then I get quite upset and then I do things I shouldn't, like eat what I shouldn't.*

Later, Patricia adds:

*I know the problem of having an area set up for someone who is diabetic to inject themselves then brings on other problems... drug addicts and that sort of thing, but when we're doing it to save our lives... They're doing it to... for whatever reason. It is a problem.*

[Patricia; 60s; insulin; diagnosed six years]

Finding a suitable place for their injections was not the only planning issue reported; participants also reported having to adjust their schedule to ensure they had something to eat shortly after injecting themselves. Patricia herself alludes to this issue when she comments on the information she was given on how to plan her meals around her insulin injections:

Patricia: *what they kept pushing at me is you must have food within fifteen minutes of having your insulin. And I became quite paranoid about it, so I got to the stage where, unless the food was sitting in front of me, I wouldn't have the insulin.*

Interviewer: *because you were worried...?*

Patricia: *because I kept thinking I don't want to pass out, and so... I still try and do that, in fact, I don't have it unless I know... if I go out to a shopping centre I have to go and get the insulin, then I worry in case something happens [chuckles] if I'm getting whatever I'm getting for lunch, you know, sort of thing. But it's never happened and I don't expect it to happen, but I try and not eat when I go out to shopping centres. I eat before I go, so it's not a big problem these days.*

[Patricia; 60s; insulin; diagnosed six years]

Similarly, Dot also touched on the issue of planning her meals around her insulin. As she reflects on the impact of diabetes on her working life, Dot discloses that she was retired on health grounds because she was unable to cope with the demands of her insulin regimen:

*As I said, I've always worked, until I was retired because of my doctor... because of my health at one stage, when I was retired I... I wasn't coping because... that's when I was first put on insulin and the fact that I was dealing with food all day long... I wasn't eating, and having to have insulin, I just wasn't coping. I wasn't eating at all... and, as you know, with insulin, you have to eat [...] and I wasn't doing that, so it was... it was creating a problem for me, so that's when the doctor retired me on*



*my health. But I had a good long working life, you know, so... Uh... so it just sort of... it impacted on me, I supposed, after I left work, because I loved my job.*

[Dot; 70s; insulin; diagnosed 35 years]

Gaining weight was reported by participants as a negative side-effect of being on insulin. Mary, an Aboriginal participant who reported injecting insulin once a day, referred to her weight issues during her interview; when discussing her medication regimen, Mary comments:

*My goodness I don't like my tablets, but I take them on time. And insulin at night, I have. That's making me so big around here [points to her stomach].*

[Mary; 60s; insulin; diagnosed 15 years]

The issue of weight gain was also raised by Cathy and Rachael, two Aboriginal participants who took part in a joint interview. Cathy reported being on remission from cancer and having trouble gaining weight, and I observed that she looked frail. On the contrary, Rachael reported struggling with her diet and constantly worrying about her weight. Following a comment by Rachael on her insulin regimen, the following exchange takes place:

*Cathy: they reckon the needles are the best.*

*Rachael: yeah, well, what I find is that they make you more hungry. [...] The insulin makes you hungry, and I'm eating more. Well, I find that.*

[Cathy; 70s; tablets; diagnosed 12 years. Rachael; 60s; insulin; diagnosed 20 years]

Cathy's comment appears to refer to insulin's stabilising effect on glucose levels, which was the only positive comment on insulin reported by participants. Patricia, who reported being 'very steady' with her readings, also alluded to this perceived positive effect of insulin. Asked whether she monitors her BSLs, Patricia responds affirmatively, and her account reveals the role insulin has played in stabilising her glucose levels:

*I do, and they're between 4.8 and 5.5, 5.6 if I'm not feeling well, which in the last week or so I haven't been totally well, and I can go up to 6.2, but I have never, since I've been, since they got me regulated with the insulin, I've never been over that.*

[Patricia; 60s; insulin; diagnosed six years]

Similarly, Bridget explained that her BSLs had been more stable during the last two years she had been on insulin; and even her husband Cecil, who had been on insulin for only two weeks at the time of the interview, reported noticing a positive difference.

### ***Self-monitoring of blood glucose***

The analysis of participants' account revealed a range of experiences with regard to self-monitoring of blood glucose (SMBG). A total of 14 interview participants reported performing SMBG regularly, and they included participants on different management regimens: six reported being on insulin, a further seven reported being on tablets, while one reported being on diet-only management. Participants' reports of frequency also varied, from a maximum of three times a day to a minimum of 'every few days', although the most commonly reported frequency was once a day.

On the one hand, some participants' accounts suggested that they had a strict SMBG routine in place; they reported monitoring their BSLs regularly and often, and a few even showed me their BSL log-books. On the other hand, several participants reported not monitoring their BSLs even though they owned a glucometer, and they provided a range of explanations: Mary, an Aboriginal participant who reported that her BSLs were 'normal', claimed that her glucometer was not working; while Liz reported that although her husband Bill had a glucometer, she did not use it. Liz provides a tentative account which suggests that she does not perceive the need to perform SMBG:

*I haven't done because... I'm never sure why I haven't done it but I've always been alright, so... the doctor's never insisted that I ...*

[Liz; 60s; tablets; diagnosed four years]

As for Bill, who came across as having a very positive outlook on life, he facetiously comments on his experience of using the glucometer:

*Bill: every time I use it something goes wrong with it, it's like me and the TV [chuckles].*

*Interviewer: so you don't check it or anything?*

*Bill: no. You can sort of pick it, oops that's the sugar levels coming up. It's something that's there and then you go, come on, I'll cut it again. I sort of lie back on some of the meals... and I'm as good as gold.*

[Bill; 60s, tablets; diagnosed 10 years]

In his comment, Bill reveals that he can ‘pick’ that his BSLs are raised and he uses his awareness of the physical symptoms he experiences when he is going through a hyperglycaemic episode to adjust his diet accordingly. Bill’s account suggests that he perceives this strategy as a valid alternative to using the glucometer.

Tony’s account provides an insight into how his SMBG routine has changed over time. When asked whether he checks his BSLs, Tony responds affirmatively, but his tentative account suggests that he might not do it regularly:

*Tony: I hate pricking myself, you know, I mean I should get one of those machines that do it, you know, tsheek! You know, I’ve got one but yeah... I do, but sometimes I forget, you know... uh...*

*Interviewer: so how often would you do it?*

*Tony: uh... when I first got it, I used to do it every [emphasis] night, pricking my leg, pricking my finger, and I hated doing it! My wife used to do it, you know, for me. ‘Cause I can’t do it myself. And now I just do it on my leg, you know, I get a pin and do it on my leg and test it. Because I can’t do it... I don’t get much blood out of... when I prick the end of my finger. [...] You know, I play the guitar sometimes, and I can’t... sometimes I can’t, because it’s too, you know...*

*Interviewer: too hard?*

*Tony: too hard, yeah. [...] So, yeah, I do test it, but not as much as I should do. I should... when my wife was here I did all that, but... you know, being...*

*Interviewer: how often would you do it?*

*Tony: truthfully?*

*Interviewer: yes [chuckles]*

*Tony: maybe once a week.*

When asked whether he records the results on a log-book, Tony admits:

*I used to; but as time goes on and on and you live by yourself... I’m just myself, you know, I just think argh... but I can tell when my diabetes is up very high... I get a funny taste in my mouth.*

[Tony; 50s; tablets; diagnosed 10 years]

Similarly to Bill, Tony mentions that he experiences physical symptoms – in his case, ‘a funny taste’ in his mouth – which alert him to his raised glucose levels, and he also seems to perceive this as an alternative to using a glucometer.

A worrying account is provided by Peter, a participant who reported BSLs in the 16-18 range, hypertension and heart disease. Peter reflects on why he has stopped monitoring his glucose levels, and his account conveys a sense of fatalism:

*Well, I haven't been because it's pointless, I can't get them down so what's the point of monitoring every day.*

[Peter; 50s; tablets; diagnosed seven years]

Participants who did report having a SMBG routine in place commonly reported that the frequency of monitoring had decreased over time. Patricia talks about how and why her SMBG routine has changed over time, and her account reveals how she also uses the physical symptoms she experiences as a marker for raised BSLs:

*Patricia: I used to do it four times a day, cut back, so now it's every few days I'll do it.*

Interviewer: *alright.*

*Patricia: unless I'm not feeling well as far as the diabetes.*

Interviewer: *and you know your body well enough to know that?*

*Patricia: yeah, up to this time, yes, so... if I need to do, I do it, and if I don't, I don't. There's no point in sticking a needle in yourself; no. I have enough of that.*

[Patricia; 60s; insulin; diagnosed six years]

Similarly, Dot, who has been diagnosed for 35 years and reported coping well with her diabetes, comments on the changes to her SMBG routine over the years:

*I do, but I've got to admit, I'm very naughty, I'm not going to lie about it. It's just that I've got to a stage that I'm not as... good as I used to be. Uh... I suppose I should, but I don't. But I do have the machine. [...] I think that's one of the things I do pull down on, is doing my sugars.*

[Dot; 70s; insulin; diagnosed 35 years]

## Conclusion

Self-management was experienced as a routine which entailed a number of lifestyle and clinical components, and brought about a number of adjustments to everyday life. Diet was perceived as the main component of diabetes self-management, and there was a common understanding of the dietary requirements for a person with diabetes. Resisting cravings and giving up favourite foods were identified as barriers to achieving a healthy diet, and participants faced access issues relating to depending on others for food provision, and accommodating the price of healthy food within a

limited budget. Eating was experienced as a social practice, and family and social circumstances influenced eating and cooking practices.

Exercise was perceived as an important component of diabetes self-management; however, there was little evidence of regular physical activity. Narratives on exercise were mostly framed in a negative way; and lack of motivation, co-morbidities and mobility issues, cost, and neighbourhood safety concerns were reported as barriers.

Experiences of the clinical component of self-management varied depending on the regimen: taking tablets was largely experienced as an accepted easy-to-follow routine, while insulin injection was associated with notions of fear, rejection and stigma. There was inconsistent evidence of SMBG.



## **Chapter 8 – ‘My Diabetes is Full of Stress’: The Experience of Living with Diabetes**

In this chapter, I present the findings of participants’ attitudes towards and experiences of living with diabetes. The results presented in this chapter complement those presented in Chapter 7, and relate to the study’s first objective:

To explore the attitudes and experiences of disadvantaged persons living with T2D with respect to living with and self-managing their disease.

### **Participants’ experience of disease**

In this section, I begin by discussing the impact of diabetes on participants’ well-being, including reports of general fatigue, experiences of the symptoms associated with hyperglycaemic and hypoglycaemic episodes, and the impact on emotional well-being. This is followed by the results relating to participants’ experience of diabetes as a family disease, where I explore how this experience shaped participants’ attitudes and experiences of their own diagnosis, their understanding of diabetes as a progressive disease, and their fear of the potential complications of diabetes.

#### ***Impact of diabetes on well-being***

Participants’ accounts of their experience of living with diabetes were dominated by the negative impact of diabetes on their physical and emotional well-being. Participants reported experiencing general fatigue; they also suffered from a range of symptoms when they experienced hyperglycaemic or hypoglycaemic episodes; and reports of foot pain associated with peripheral neuropathy were also common. In addition, participants reported that diabetes had affected their emotional well-being, with many reporting feelings of irritability and mood swings.

The most commonly reported physical side-effect of diabetes was general fatigue, which participants described as feeling ‘sleepy’, ‘drowsy’, ‘tired’, ‘exhausted’, ‘lethargic’, or ‘sluggish’. My observations of participants were consistent with their reports. For example, I observed that during the sessions some participants yawned, sounded lethargic and looked tired; during the conduct of the Indigenous focus group one participant had difficulty staying in the discussion as she was constantly falling

asleep; and during the conduct of one of the interviews one participant had great difficulty focusing on the conversation, and his account became vague and his speech slurred towards the end of the session, which I attributed to a decrease in his glucose levels.

Although most participants reported feeling tired and lacking energy, their experience of and attitude towards this general fatigue varied greatly depending on their reported levels of glycaemic control. Participants who reported good glycaemic control and whose narratives indicated a high level of self-efficacy tended to explain their tiredness in the context of getting old and ‘slowing down’, rather than attributing it to diabetes. Bill, who reported having ‘no hassles whatsoever’ with his diabetes reflects on the impact of diabetes on his life:

*It slows you down a little bit, but you sort of slow down as you’re getting older, that’s what I feel. It’s slowed me down a lot, and I find I’m not as strong as I used to be. Once I could lift all this heavy weight in front of me. Now I find I can’t do it, but that’s the effect it’s had on me. And, like I said, the eyesight; that’s the only thing. So now I’ve got to wear glasses and that, but other than that it’s never really had any effect on me.*

[Bill; 60s; tablets; diagnosed 10 years]

Similarly, Paul, who reported being very disciplined about his diet-only regimen, referred to the fact that he was getting old several times during the interview. As he makes a comment about the deteriorating condition of his feet, Paul’s account conveys a certain sense of resignation:

*Like I said, my feet are getting... are not getting any better, I’ve become a lot more conscious. At present they’re not too bad, but it’s constant; it’s not like a backache and then it goes. This one never goes, stays there, it’s always there. I could sit in here, and sometimes I think I’ve cut out my blood supply, you know... it could be that, but the doctor said, ‘you’re getting old, you know’... Alright; fair enough.*

[Paul; 80s; tablets; diagnosed 18 months]

Paul’s account highlights another physical side-effect of diabetes, that of sore or ‘burning’ feet, a symptom associated with peripheral neuropathy often observed in people diagnosed with diabetes, which was also reported by other participants and cited as a barrier to exercise (see Chapter 7).

Bill’s wife Liz also refers to her age as she comments:



*'Cause I have noticed lately that I do get tired, and whether that's anything to do with the diabetes or age, I don't know.*

Later in the interview, when asked whether there are days when she feels worse than others, Liz provides alternative explanations of her tiredness:

*No, not really. Sometimes I feel tired, but whether that is because I haven't slept or whether it's because I got up later and I haven't had my tablets or something like that; and I sit in the chair in the lounge room and fall asleep. So I do know that if there's anything I desperately want to see on TV I tape the show, because I know I'm going to fall asleep.*

[Liz; 60s; tablets; diagnosed four years]

Leah, an Aboriginal woman who took part in the non-Indigenous focus group, is the only study participant who reported being employed at the time of the interview. As Leah describes her daily routine, her account provides an insight into her fluctuating energy levels, possibly aggravated by the physical demands of her work as a cleaner:

*See, I get up to work at ten to four, and by seven o'clock I'm weak, and I finish at nine so... And I ride to work, about 40 minutes and just... just working all... and then I get all slack...and I'll be thirsty, and I'll have water or diet coke, but by seven o'clock I'm just winding down. And I get home and I get some breakfast, have my tablets, have a sleep, get up and get back to work the afternoon shift and then I start at two, and around about four I start getting drowsy.*

[Leah; 30s; tablets; diagnosed eight years]

Alison, who reported being highly motivated since being on a drug trial, provided a similar account. She initially comments on the positive impact of being on the trial on her quality of life, referring first to her increased energy levels:

*Well, number one, so much more energy. I don't feel tired, lethargic, as much as I did. Losing weight has given me a lot more mobility, it's improved my back condition; it has just improved my life dramatically.*

However, later in the interview, Alison acknowledges:

*Sometimes I do feel quite tired, which is a symptom of diabetes. I do, actually... you know, even though I may have had a good night's sleep, which is a little bit rare for me, I don't sleep well. But, uh... even though I might have had a rest, I can sometimes still feel quite tired. Some days it can actually be quite an effort to do the things that I require of my day.*

[Alison; 50s; tablets; diagnosed eight years]

Feeling tired and experiencing low levels of energy was commonly reported by Derbarl Yerrigan clients. An exchange between Joan and Gail illustrates the impact of diabetes on their physical well-being, and provides an account which is representative of the experience of many participants:

Joan: *um... at night I'm so tired, I can't sleep.*

Interviewer: *because you're so tired?*

Joan: *I'm so tired... whether it's the diabetes, I don't know.*

Gail: *I suffer from that too, I get tired.*

Joan: *you know it drains you.*

[Joan; 70s; tablets; diagnosed five years. Gail; 70s; insulin; diagnosed 20 years]

Regardless of their level of glycaemic control, most participants reported experiencing specific physical symptoms when their glucose levels were either too elevated or too low. In participants' accounts, hyperglycaemic episodes tended to be associated with headaches; while hypoglycaemic episodes ('hypos') tended to be associated with feelings of light-headedness, or, as Sheryl vividly describes it:

*As if your batteries are going flat.*

[Sheryl; 60s; tablets; diagnosed one year]

Participants whose narratives indicated poorer glycaemic control tended to report experiencing more frequent hyperglycaemic and hypoglycaemic episodes, and they also tended to report more severe side-effects, which they described as feeling 'faint', 'shaky' or 'giddy'. Peter, who reported glucose levels in the 16–18 range, provided an account which illustrated the extreme fatigue he experiences. Peter reflects on what he experiences as the most difficult aspect about living with diabetes:

*The hardest thing is the tiredness, no energy, no sort of go. I find that's the hardest thing, it's trying to get the steam to do anything.*

Later, he adds:

*It's a very depriving disease; as I said, if you get too much glucose in you, you become very tired, you become very lethargic, no sort of energy drive, so it just lets you in a state where you're tired, no energy. You just feel a slump on a chair, and that does, I guess, over a period of time, get worse and worse and worse... you know, getting up at 11 o'clock in the morning, falling asleep.*

[Peter; 50s; tablets; diagnosed seven years]

Tony, a participant who also reported high and unstable blood sugar levels, provided a similar account. When asked to describe what living with diabetes is like, Tony responds by describing a recent episode:

*Uh... living with diabetes is... for instance, the other day, when was it? Monday. It was a nice day, Tuesday... I can't remember, uh... I was feeling really good, uh... ankle, back was feeling OK, I was feeling good in myself. Get up early, I laid the lawn, uh... I did some sweeping up, uh... swept the garage, and did this and the other, ran the vacuum through, uh... I didn't stop for any morning tea, I had two bits of toast and a cup of coffee in the morning... By maybe two o'clock, uh... I feel very faint because, you know, I've used up all the... and uh... I had to come in here, and I ate myself stupid, you know, whatever was in that fridge, you know, sandwich... and I must have eaten eight bits of bread before the shakiness went.*

[Tony; 50s; tablets; diagnosed 10 years]

Tony's account highlights the potential impact of not having regular meals. Tony talks about eating bread as a way of recovering from a 'hypo', and, later in the interview, he also reports drinking *Coca-Cola*® when he feels shaky. Similarly, Frances, an Aboriginal woman who reported feeling very tired all the time, talks about how she gets over her 'hypos', as she asks a question which appears to have been on her mind for a while:

*Now, tell me all about Coke, because when I feel sick and giddy, the only thing that makes me feel good is something that they reckon you shouldn't have, and that's Coke.*

Later, Frances describes how she feels after drinking Coke:

*I feel good; then I can walk around. If I don't have that Coke, I'm finished. I can't see nothing and I'm sick and I'm giddy. But Coke fix me, and they say don't drink Coke.*

[Frances; 70s; tablets; diagnosed 40 years]

Frances' account reveals her limited understanding about what triggers her 'hypos', and her confusion about whether Coke is good for her or not. In her experience, Coke makes her feel 'good' and she clearly has trouble understanding why 'they' (the doctors) say it is not good. I had observed Frances falling asleep during the focus group, and most Derbarl Yerrigan clients with whom I spoke were concerned about her, and believed she needed more education about her condition.

Lee describes how she feels when her BSLs are elevated:

*I notice that when I do have sugars, I have prickles and tingles on my thighs, on my hands, my elbows and my knees, kind of thing. And I find that very uncomfortable and it sometimes went into cramps, and sometimes... I have had this for about four years before it was actually diagnosed, at different times. I would wake up in the morning light-headed and kind of 'déjà-vu', and uh... I think for about four years before I actually had it. I do know that there were vast mood swings, and that wasn't a good thing. And I think it had to do with sugar levels as well. But uh... and sometimes I feel very, very grouchy, and I think it's part of what's going on, and I don't understand it.*

[Lee; 60s; tablets; diagnosed with hyperglycaemia one year]

Lee's account reveals a range of symptoms which she attributes to her condition: prickles and tingles, cramps, feeling light-headed and 'déjà-vu'. Lee also reveals her experience of the impact of her condition on her emotional well-being, as she refers to feeling 'grouchy' and experiencing mood swings. Similarly, Sheryl recalls the vague symptoms she experienced as she was going through menopause and, in hindsight, compares how she felt then and how she feels now when her BSLs are too low:

*I remember years ago, when... before I went through the change of life, I was having these turns where I couldn't have been able to tell you my name, and I would never drive because I couldn't tell the difference between the light colours... And I personally think it might have been the diabetes thing... 'cause I know what I used to feel like then, and what I feel like now if my blood sugar's down.*

[Sheryl; 60s; diet; diagnosed one year]

The same connection between the signs of menopause and the side-effects of diabetes was made by Lorraine, a participant in her early seventies who reported feeling symptoms similar to hot flushes when her BSLs were elevated.

Participants' reports of the impact of diabetes on their emotional well-being included feeling emotional, short-tempered and frustrated, and having mood swings. Lee, whose account suggested that she struggled to accept her diagnosis of hyperglycaemia, became emotional several times during the interview. At one point, Lee had to leave the table to fetch a tissue as tears were streaming down her face. As she comes back, Lee comments:

*There's no control over it, or there isn't a... well, I always feel very, very emotional as a person, and that seems to have escalated it.*

[Lee; 60s; tablets; diagnosed with hyperglycaemia one year]

Michael, a participant who reported high glucose levels and whose account revealed that his quality of life had deteriorated recently due to a build-up of fluid in his brain, also talked about the impact of diabetes on his emotional well-being:

*Another thing about being diabetic... very short-tempered, I am. I get very tired and frustrated.*

Incidentally, Michael was the only study participant who mentioned the negative impact of diabetes on sexuality. He brings up the issue unprompted at the beginning of the interview, suggesting that this is of particular concern to him:

Michael: *and then, since uh... what do you call it? This diabetes became worse, my sex life has gone too as well; so... that was it.*

Interviewer: *so it has impacted on that aspect as well?*

Michael: *yeah, that's right. And that disappointed me a bit, so, you know...*

[Michael; 60s; insulin; diagnosed 15 years]

Overall, participants' accounts revealed that the deleterious effects of diabetes on well-being coloured their everyday lives.

### ***Diabetes: A family disease***

Participants' narratives revealed that most had a family history of diabetes. Typically, participants could identify several members of their family affected by diabetes, and, in most cases, these were close relatives such as parents, grand-parents and siblings. Participants' accounts revealed that being witnesses to the diabetes experience of others around them influenced their own experience of disease, and their attitude towards self-management. In particular, the experience of diabetes as a hereditary disease shaped: their experience of diagnosis; their understanding of diabetes as a progressive disease; and their fear of the potential complications of diabetes.

### **The inevitability of diagnosis**

Participants' reports of the circumstances of their diagnosis varied; however, their accounts showed that most had experienced the onset of diabetes as an inevitable and expected occurrence, because of the history of diabetes in their families. Sheryl reflects on her concerns about her son's health, which leads her to discuss her family history of diabetes:

Sheryl: *He's put on a lot of weight, and I keep saying to him, you know, about the diabetes. I say, 'you know, diabetes is rampant through the family'. 'Cause my mum was diabetic, my brother next to me is diabetic, uh... I mean there's eight of us, and I think my other brother's sort of borderline, and my other brother he's diabetic, he was diagnosed before I was, and, uh... same as the one in Hedland [country town in northern WA], they found him flipped out at his job, you know, and he's diabetic, so it's sort of everywhere. Mum's sisters were and that sort of thing in the family, yeah, so, yeah. And I'm the bigger... the bigger person now, but they weren't. And it's not because you've got that extra size, it's just that it's in the family, yeah, so... it's sort of hereditary I suppose, yeah.*

Interviewer: *it seems to run in the family...*

Sheryl: *yeah, yeah, yeah. My brother next to me, he's got it, he's on... some tablets, but he's just skin and bone, you know, so... and the one that's over East he's never been like overweight or anything, so... but he's been diabetic for years before I was, so, it's just... yeah...*

[Sheryl; 60s; diet; diagnosed one year]

Sheryl's comment is revealing because it points to her perception that there are two types of diabetics: those who develop diabetes because they are overweight, and those who have a history of diabetes in their family, irrespective of what Sheryl describes as having 'that extra size'. This perception that some people bring diabetes onto themselves through lifestyle choices, while others develop diabetes through 'no fault of their own' was common among participants, as many attributed the onset of their diabetes to heredity rather than lifestyle.

Having a family history of diabetes appeared to bring with it a certain sense of fatalism; this is present in Mandy's account when she talks about being diagnosed with impaired glucose tolerance (IGT):

*I think it was in 96 I was first put on the diabetic diet, and yes... So I held it off, I think, pretty well. So it was quite a while before it did actually catch up with me, so... yeah... But I think, with it being in the family, it was inevitable that I was going to end diabetic, yeah...*

[Mandy; 50s; tablets; diagnosed two years]

Mandy's choice of words is illuminating, as she talks about how she 'held off' diabetes before it 'caught up' with her, suggesting that she perceives this progression as an unstoppable process despite her best efforts. This sense of fatalism was shared by many other participants, and featured very strongly in the accounts of Aboriginal participants. Renee, the only participant who reported being on dialysis, encapsulates this view when she comments:

*Our history is bad for the disease, you know... the sugar disease.*

As for her own diagnosis, she reflects:

*Well, I didn't want to have the sickness. I knew it was going to come because my family had it through the genes; that's why I knew I was going to get it.*

[Renee; 50s; dialysis; diagnosed 20 years]

Alison talked about how her diagnosis came about, and her narrative is representative of the journey reported by many participants. She comments on her family history and recalls her own diagnosis:

*Uh... well, diabetes is in my family. My mother was diabetic; she's now deceased. My father is type 2 diabetic; he's still with us. Uh... there's a lot of family... we... we don't have much family in Australia, they're all in England, but uh... going back for three generations there's diabetes all through both sides of my mother's and my father's family, uh... Quite a few in my mother's family are type 1 diabetics, so I was aware that I had the genetic predisposition to developing diabetes, and when I was about, oh, thirty-five I think it was, my... the GP at that time said 'what you should start doing is every three or four years have your blood sugars checked just to keep an eye on it, Alison'. [...] Uh... and I'd been doing that, and it was always fine, and then we did it... I did it one year, and the doctor said, 'oh gosh, it's almost, it's borderline, so you'd better start being a little bit more vigilant', he said, 'come back next year and have them tested'. Well, when I went back it'd gone way into diabetes; it was quite bad, actually, at that time. But I'd been... the reason I went back earlier than planned was I'd been feeling quite unwell, I'd been feeling, you know, very tired, excessively thirsty, urinating excessively, and I knew those were the symptoms of diabetes, so... that's why I went.*

[Alison; 50s; tablets; diagnosed eight years]

Alison's account reveals that her familiarity with the symptoms of diabetes prompted her to consult her GP earlier than originally planned. Similarly, Bridget recalls how her husband's diagnosis came about:

*'Cause I had concerns that he had diabetes. He was sleeping a lot, and I said to him, I said, 'you've got all the signs of diabetes', he said 'don't be silly', I said 'let me test you'. So I used my machine, I tested him, and it was sitting up on 38.6. I'll never forget that day. And I said to him, 'I'm taking you to hospital'.*

[Bridget; 40s; insulin; diagnosed seven years]

Several participants, however, reported an experience of diagnosis which was very different to that described by Alison and Bridget. For Peter, for example, the

diagnosis came about as a result of his hospitalisation for a heart attack; while for Patricia, diagnosis followed a traumatic hospitalisation caused by extremely elevated BSLs, which resulted in her being placed on insulin shortly afterwards.

Although most participants experienced their diagnosis as expected, a few participants reported struggling to come to terms with it. Lorraine, for example, reported not understanding how she could have ‘caught’ the disease, even though she had a family history of diabetes. Lorraine reflects on the onset of her diabetes:

*I couldn't understand why I caught it, and I didn't sit down and binge on chocolate all the time. If... if you binge on those sorts of things, you get that sort of thing. 'Cause I know my husband, when he got his sugar diabetes, he was addicted to Coke, he could not... every time you saw him, he had two-litre Cokes, and one after the other, 'cause he couldn't stop drinking, that's all he wanted!*

[Lorraine; 70s; tablets; diagnosed three years]

Lorraine's account reveals her perception that some people bring the disease upon themselves through lifestyle choices, and it is clear from her comment that she does not perceive herself as being in that category. Meanwhile Martin, who reported taking medication for depression and appeared to have been deeply affected by his marriage breakdown, questioned why he had developed diabetes and offered his lay explanation of causality. Martin reported that the strong medication he had initially been prescribed for his depression had affected his liver function, and he believed that it might also have affected his pancreas, causing him to develop diabetes.

### **Diabetes: A progressive disease**

Participants had a common understanding of diabetes as a progressive disease. Their accounts suggested that this understanding was underpinned by a ‘diabetes continuum’ or ‘diabetes scale’ construct, where those on diet and exercise management were located at the lower end of the scale, and those on insulin – sometimes referred to by participants as ‘type 1 diabetics’ – were at the higher end. In this context, IGT was perceived as a precursor to ‘full blown’ or ‘proper’ diabetes.

Within these parameters, participants typically positioned themselves and their disease somewhere along this ‘diabetes continuum’, and commonly defined themselves as ‘good’ or ‘bad’ diabetics by comparing themselves to others. During her interview, Liz described a friend as a ‘very bad diabetic’, alluding to the fact that



her friend – Patricia, who was also interviewed – was on insulin and had experienced diabetes complications. Similarly, Liz’s husband Bill compared his diabetes with his wife’s. In his comment, Bill uses the number of tablets each of them takes as a means to establish their ‘ranking’ along the ‘diabetes continuum’:

*She’s not as bad a diabetic as I am. I’m what they call borderline diabetes, she’s a bit above that, she’s not as bad as me. She doesn’t take the same tablets as me. She takes some of the tablets, but not the same. I take, what, five in the morning or something, and one at night, that’s about it. And she takes two in the morning, and two at night; I think that’s what she takes.*

Later in the interview, Bill confirms his understanding of where he perceives his diabetes to be positioned along the disease continuum when he comments:

*I’m only type 2 diabetes, where anybody who’s got type 1 [...] that’s a different kettle of fish, you know, because they’re on insulin...*

[Bill; 60s; tablets; diagnosed 10 years]

Patricia, the friend Liz described as a ‘very bad diabetic’, also positioned herself along the continuum by comparing her situation to that of her sister’s, who is ‘only’ on tablets. Interestingly, Patricia describes herself as a ‘mild case’ in the following comment, and uses the number of units of insulin she injects as a way of quantifying the severity of her disease. Patricia reflects on how diabetes has affected her life, and after describing her insulin regimen, concludes that she does not have a ‘big problem’:

*I stick four needles a day in myself. That’s it, you know. But other than that, I can’t see how it changes... Oh yes, I have extra doctor’s appointments and stuff like that, but other than that I can’t see for me... As I’m a mild case, I mean I take six units in the morning, three at lunch time, five at night-time, and ten before going to bed. I don’t think that’s a bad diabetic. So really I don’t have a big problem.*

[Patricia; 60s; insulin; diagnosed six years]

Similarly, Michael and Rose used their respective insulin regimens to compare each other’s disease status – incidentally, their accounts revealed a lack of consistency, suggesting that they were not aware of each other’s regimens. Michael talked about Rose being on 14 or 15 units of insulin ‘only’, while he is on 60; while Rose, who during the interview came across as being frustrated with her husband’s lack of control over his diabetes, and constantly compared her strict approach to what she

perceived as Michael's low self-control, talks about her insulin regimen, and immediately refers to her husband's as a contrast:

*It's thirty in the morning, and thirty in the evening. Yeah... I know it's a bit high, but... compared to Michael, it's forty or fifty, oh my God!*

[Rose; 60s; insulin; diagnosed 20 years]

Participants' accounts also revealed that they perceived diabetes as having stages, and the fear of progressing from one stage to another shaped their experience of disease. Paul articulates this view as he reflects on how he has managed in the last few years:

*I stopped the coming of proper diabetes for about seven or eight years, but now I'm still at the stage where doctors say I don't need medication. So there must be stages in your life in diabetes, first ... then diabetes without medication, and that's where I am now. I hope to stay there.*

[Paul; 80s; diet; diagnosed 18 months]

Paul uses his understanding of the 'stages' of diabetes to motivate himself to stay where he is, that is, on a regimen which does not require medication. Similarly, Sheryl, the only other participant who reported being on a diet-only regimen, reflects on her self-management:

*I have to do what I have to do to keep it under control, 'cause I really don't want to go on medication, so that's... if I can keep going so that I don't have to have medication, that's... that's my goal, out of it all, it's to do that.*

[Sheryl; 60s; diet; diagnosed one year]

For those participants already on a medication regimen, becoming insulin-dependent was a possibility that seemed almost too hard to contemplate. Peter reflects on how his life has changed as a result of his diagnosis:

Peter: *uh... well, it's changing. I'm changing it now because I don't have a choice. Either I change my diet, or I'm going to die with it, and I don't want that. Or else it'll go from diabetes 2 to diabetes 1.*

Interviewer: *as in being insulin-dependent?*

Peter: *yeah, become insulin-dependent, and from there I can't go anywhere, so... I don't want to get into that category, I much rather...*

[Peter; 50s; tablets; diagnosed seven years]

Peter's comments highlight his fear of becoming insulin-dependent. Similarly, Tony reveals his dread of needles, which he associates with insulin dependency, as he recalls his brother's experience:

*I remember from my brother, giving needles and that... you know, it's very hard for... I feel sorry for the children that have got it... diabetes. I've only got type 2, but I would hate to have the type 1, I'd dread it! Really! You know, and a lot of people live with that every day, and they're worse off than me.*

[Tony; 50s; tablets; diagnosed 10 years]

Thus, most participants expressed their fear of progressing from being a 'good diabetic' to a 'bad diabetic', and their accounts revealed that this fear was driven by their experience and understanding of diabetes complications.

### **The fear of diabetes complications**

Many participants reported having seen close family members or friends experience severe diabetes complications – such as amputations or renal failure – or even die as a direct or indirect consequence of diabetes, and these experiences shaped their fear of disease progression and diabetes complications. Peter provides a vivid comment which encapsulates this fear:

*Well, I don't want to wind up like my aunty, in a wooden box six foot down...*

[Peter; 50s; tablets; diagnosed seven years]

Participants' narratives revealed that witnessing the complications of diabetes in others around them influenced their reaction to their own diagnosis. Alison, who reported good glycaemic control since being on a drug trial, reflects on the impact of diabetes on her life and recalls her initial reaction to her diagnosis:

*Alison: oh, well, uh... well, I suppose just... just the knowledge of it, you know; I now have... I now know I have a serious illness; I now know that. Uh... there are very serious potential complications along the way, that, you know, it's actually life-threatening, which a lot of people, until you explain that to them, they actually don't know that diabetes is quite life-threatening, so... that's... that's scary, you know, even though, you know... well, I suppose... probably because I watched my mother die of diabetic complications, it was quite scary ... [pauses]*

*Interviewer: do you think that that experience, seeing that your mum died of diabetes, made that you were perhaps more frightened when you got the diagnosis?*

*Alison: yes, it did. I'm sure it probably... it shouldn't have, but being really honest, I'm sure it played a part in my not... not managing it properly; I didn't want to know, I didn't want to go there. And I realise it was very foolish of me and that I shouldn't have done that, I shouldn't have left it for those couple of years where I just coasted along...*

[Alison; 50s; tablets; diagnosed eight years]

Alison's comments reveal that her personal experience of the potential complications of diabetes not only shaped her experience of diagnosis but also led to her initial denial of her condition and her reported non-adherence to her self-management regimen.

Lee provided a similar account, and her narrative suggested that the trauma of seeing someone close to her experience severe diabetes complications still affected the way in which she experienced her condition. Lee reported having been diagnosed with hyperglycaemia and having been prescribed diabetes medication; she also reported not having had her BSLs tested or seen a doctor for her condition for several months. Her narrative suggested that Lee was frightened by her diagnosis, and was still struggling to come to terms with it. In her account, Lee acknowledges her fears and her voice fills with emotion as she recalls:

*As a child I saw a man have full-blown diabetes. He was a family friend, and he had a leg amputated four times [sic], and it was a slow, debilitating disease, and it was awful to watch. And I think that there is horrendous fear there as well. But I know that we have come a long way medically, and I know we're a lot wiser than we were when I was a child, and that was in the fifties. And I have to give that away. But I understand that if you don't take care of it, you don't exercise, that will be one of the problems.*

Lee's fear of diabetes needs to be understood in the context of her fear of disease generally, which appeared to be shaped around her experience of watching her mother die of liver cancer. Lee becomes emotional as she recalls this traumatic experience:

*My mother had liver cancer [...]. They opened up her gallbladder and she had small tumours on her liver. Uh... they took both breasts [...] because there were... they found tumours in them, coming from this liver cancer. Uh... it took eight years for her to die. I can't even begin to tell you the pain, suffering, and, you know, the rest of it...*

[Lee; 60s; tablets; diagnosed with hyperglycaemia one year]

Bill, who came across as being relaxed and having a very pragmatic temperament, talks about his family history of diabetes, and reflects on the impact of watching his mother getting sicker:

*Bill: like I said, diabetes has never worried me. I think a lot of it, it could come back to growing up with it.*

Interviewer: *like seeing it around you?*

*Bill: yeah, like, my mother and all her brothers and sisters, and her own mother, they all had diabetes. And looking after... 'cause I looked after my mum for about six years, and it just didn't worry me, it's sort of... it's there, you've gotta put up with it. The only thing that did worry me was watching her getting sicker and sicker and sicker. That was the biggest thing.*

Later, he adds:

*When I get bloody old, I'll start getting crook with it, and that's when it's going to start worrying me.*

[Bill; 60s; tablets; diagnosed 10 years]

Bill's account unveils both positive and negative aspects about having a family history of diabetes: on the one hand, Bill appeared to have coped well with his diagnosis as he knew what to expect and he 'put up with it'; on the other hand, even somebody who reported taking things in his stride had clearly been affected by watching his mother's condition deteriorate, and this experience shaped his concerns about what the coming years might bring.

Some participants' accounts suggested that they used the fear of seeing their physical health deteriorate to motivate themselves. Leah talked about the fear of ending up like her aunty, who had been very ill with diabetes and had been hospitalised. When asked how she manages to keep her diabetes under control, Leah replies:

*By exercising. And the fear steps in again... like, don't get lazy, don't stop doing what you're doing because you will go backwards; just cruise along... I don't want to go backwards.*

[Leah; 30s; tablets; diagnosed eight years]

Cecil and Bridget also talked about their fear of their condition deteriorating, and Cecil referred to their goal of travelling and becoming 'grey nomads' as their motivation for keeping their diabetes under control. Similarly, Lorraine, who

reported having recently being diagnosed with angina, reflects on what keeps her motivated and why – as she facetiously put it – she does not want to ‘pop off’ yet:

*Some people when they get sugar diabetes, I know one who's got sugar diabetes and she don't care! Oh, it's there... that's it. She just keeps it level and eats whatever she wants. Me, if I ate what I wanted, it would be sky-high before I got out of bed, and to me that's a waste, you just don't want to do that. I don't want to do that, because, as the doctor said to me... he turned around and said, 'it can shorten your life, and you don't want that'. I said 'no, I want to see my great-grandchildren grow up'. I want to see the others... they're all little, my son's [children] are only small... his eldest one is nine, I think... nine, his eldest one, and the other one is only five months old. And I'd like to see them all grow up and get married, you know... I saw one son get married, [my daughter] never got married, [my youngest son] never got married, so I didn't get them, but I would like to see my grandchildren get married and have families and things. I just don't want to pop off yet. I'm going on seventy-three, but I don't want to die yet, you know [chuckles].*

[Lorraine; 70s; tablets; diagnosed three years]

During her interview, Alison recalled what it was like to watch her mother die from diabetes complications and revealed her determination to use this traumatic event as a motivation to get her health ‘into a good place’:

*I watched mum die, and mum was only 58 when she passed away. She died of nephritis, kidney problems, due to diabetes, and uh... although mum was an insulin-dependent diabetic, and I know I'm not, it was just too hard, it just... you know, too scary and too hard and, I suppose, it's a bit like an ostrich, if you put your head in the sand, you can't see it, and I really, you know, I really realise I was very foolish, and I'm never going to go back to that, I'm going to manage it properly, and I'm going to make, you know, make sure that I do everything I possibly can to get my health into a really good place.*

[Alison; 50s; tablets; diagnosed nine years]

It has to be noted that Alison's recent experience of disease and self-management was strongly influenced by her participation in a drug trial. Alison reported that the trial she had been on for several months had led to significant weight loss, and had had a dramatic impact on her quality of life overall.

Although most participants' fears appeared to be shaped around their experience of seeing a close relative or friend experience severe complications or die of diabetes, Rose provided a different account. Rose reported having worked in a hospital, and it became clear during her interview that her fear of disease progression was shaped by

her experiences in the diabetes ward. Rose recalls what she witnessed at work, and her narrative reveals how profoundly this experience affected her:

*I worked in a hospital, and my roster was every week we would have changes, so we had to go to different wards; so when I got to the diabetic ward I used to hate it. When I say hate it, it's not because I didn't like to see the diabetics; to see them suffering there. And I'd look and think 'my God, please I don't want to get to this stage', you know. So I'm very, very careful after I've seen all that so, you know... I've been to the dialysis ward, which I hated going down... I felt so sorry for these people. Some days I just ended up crying looking at them and thinking 'oh, my God, is it that bad?' Then I'd see the amputees, and... oh, it's terrible! So I try to scare Michael with that too [...] But I'm very scared [...] I know I'm going there anyway one day, with the dialysis and... you know, other things like your amputees and ulcers, and all... I'm very careful of all that.*

[Rose; 60s; insulin; diagnosed 20 years]

Rose's account reveals her fatalism about the progression of her disease – 'I'm going there anyway one day' – which was common to other participants' accounts.

The following exchange took place between Cecil and Bridget, who came across as having a very close, supportive relationship. They begin their conversation commenting on the impact diabetes has had on their lives generally, and, from that point, Bridget's account turns towards their deepest concerns and fears, which she delves into further after Cecil momentarily leaves the room:

Cecil: *it hasn't really restricted us. It hasn't really restricted our social life, has it?*

Bridget: *no, it hasn't restricted us at all.*

Cecil: *no.*

Bridget: *I think it's made us more aware of those around ... me, especially those around me [pauses].*

Interviewer: *how so?*

Bridget: *I don't know. I tend to watch my family more to make sure they're not going to step in the wrong road we did. It sounds silly, I know.*

Interviewer: *no, it's not silly at all.*

Bridget: *I'm a bit of a mother hen. We've got five grandkids and uh... I don't want to see my grandkids end up having to inject themselves because they've been silly and eaten junk food and all that when they're young. I mean, one of our daughters is very strict, she doesn't allow junk food. The other one, her kids drink Coke and do whatever they like, and they're seven and eight. I don't want to see them end up like us.*

Interviewer: *does that worry you?*

Bridget: *it does. It scares me. No... diabetes is not an enjoyable disease, it's a horrible disease. And... no, it's got so many effects on you.*

Interviewer: *when you say horrible, what things are you...? What's the hardest for you about the diabetes?*

Bridget: *[pauses] just fear, I think. Fear of my kidneys packing up or being on dialysis... I think it's fear more than anything, with me. I don't want... I don't want to be on dialysis [Cecil leaves the room]... It's absolute fear...*

Interviewer: *yes, some people have said that. That's been a concern...*

Bridget: *and I'm scared of losing him too, because he does not take it seriously enough. I'm terrified I'm going to lose him through diabetes. And we've been together thirty years. I don't want to see him go through something like that.*

[Bridget; 40s; insulin; diagnosed seven years. Cecil; 50s; insulin; diagnosed five years]

The words Bridget uses – ‘it scares me’, ‘absolute fear’, ‘I’m scared’, ‘I’m terrified’ – convey her feeling of dread, and her vivid account encapsulates the fears reported by many participants: seeing their own condition deteriorate; being on dialysis; diabetes affecting their children and grandchildren; and losing a loved one to diabetes.

## **Diabetes and the social environment**

Participants’ narratives revealed that their social environment influenced their experience of disease and their attitudes towards and experiences of self-management. Two main themes arose: the impact of stress on their experience of disease and their ability to cope with the demands of self-management; and the dual role played by social networks.

### ***The impact of stress on diabetes***

Most participants were exposed to high stress levels in their lives, and they were aware of the deleterious effect of stress on glucose levels. Participants identified the existence of competing demands – mainly relating to family dynamics and household arrangements – as the main source of stress; thus, worrying about children, grandchildren or elderly parents was commonly reported, as was family conflict. Financial difficulties were also identified as a source of stress, and one participant spoke of environmental concerns as a source of worry.



Stress featured prominently in the narratives of Indigenous participants. References to ‘stress’ and ‘worry’ were frequent, mostly in the context of discussing children and grandchildren, and family conflict. Anna’s comment sums up the experience of Indigenous participants:

*You’ll find that with Aboriginal people, grandchildren will stress them out.*

[Anna; 70s; insulin; diagnosed 15 years]

Similarly, Frances and Renee engage in an unprompted exchange during the Indigenous focus group which highlights the level of stress in their lives:

Frances: *worry... worry, yeah, that’s what kills you.*

Renee: *sometimes you stress a lot because the family gives you a lot of stress too.*

[Frances; 70s; tablets; diagnosed 40 years. Renee; 50s; dialysis; diagnosed 20 years]

This exchange triggered a discussion among participants about issues which were of concern to them, such as drug and alcohol addiction, and unemployment affecting their children and grandchildren. Renee, the only participant who reported being on dialysis (‘the machine’), shared her concerns about her adult children. In her account, she reveals her beliefs around the link between alcohol abuse and the ‘sugar disease’, which prompts Nicole to discuss her own concerns:

Renee: *[...] when you’re drinking too much, you know, it mucks your kidneys up, you end up on the machine like I am... well, it frightens them [the children], you know.*

Facilitator: *have they changed in the way they help you now? Do they help more?*

Renee: *no, not really, no. They still go out and drink, but, I mean, I say ‘you shouldn’t drink too much because, the, the... you know... our history is bad for the disease, you know... the sugar disease’. And it’s all through the drink that kills lots of my family.*

Facilitator: *yeah [silence].*

Renee: *probably if I was a drinker I wouldn’t be here today... they couldn’t even reach 50; but I’m here, I’m 54, so you know, I’ve passed that date because I wasn’t a drinker.*

Facilitator: *yeah.*

Nicole: *mine... I try to tell mine, being 20 and 25, that they could... with diabetes... and... really I should be educating them now, knowing what I know, even though they haven’t got it, but it’s really hard when they’ve*

*got a rotten diet, when they sit there all day and eat packets of lollies and stuff.*

Renee: *Yeah, lollies. [...]*

Nicole: *'cause as I said at the beginning my diet isn't that good. So really my house is really in disarray.*

[Renee; 50s; dialysis; diagnosed 20 years. Nicole; 50s; tablets; diagnosed 10 years]

Similarly, an exchange between Cathy and Rachael unveiled some of the multiple stressors in their lives. During the interview Rachael blames her unstable BSLs on stress, which prompts a discussion on the sources of their worries:

Rachael: *I worry that I run out of things. I worry about my weight all the time.*

Cathy: *I can't seem to put weight on. I put it and I lose it, and I put it and I lose it. And I start to worry thinking that the cancer's coming back.*

Rachael: *stress... I think stress plays a big part on the diabetes.*

Interviewer: *your family gives you a bit of stress sometimes?*

Rachael: *yeah, yeah.*

Cathy: *sometimes [chuckles].*

Interviewer: *all the time [chuckles]?*

Rachael: *and disagreement in the family. This year I'm going to put myself first. [...]* Yeah, I told my family, I said to my kids, 'you know, this is my life'. 'Cause I have a daughter; she's on drugs. I say, 'if you are on drugs, you go out there; you go out there, you know'. And my son, he goes out and... so when they left I felt, oh, some peace and, you know, no more stress.

[Rachael; 60s; insulin; diagnosed 20 years. Cathy; 70s; tablets; diagnosed 12 years]

Stress also featured very strongly in Frances's interview; she talks about the losses in her life and the impact they have had on her diabetes:

*I lost a grandson; I lost my big boy. And I lost my husband. Fifty-two years we'd been married. So all that, you know... I was alright with diabetes, but all this is building up inside me.*

Later in the interview, Frances disclosed her concerns about another grandson, who had been arrested and was pending on a Court case after getting into a fight. Frances provides an account of the events:

Frances: *I mean kids can do things that they want and they're stressing old people out. There's a lot of stress and feuding everywhere, jealousy...*

*He goes to town on Friday night... and there's seven, eight boys chasing him, want to fight him. He hit one man and knocked him down, because he was fighting for his life, and now the Police has charged him, and they leave all the trouble-makers go! Well, this is the kind of stress that we go through*

Interviewer: *uh-huh. And that messes up with your...*

Frances: *it messes up with my sickness and everything.*

Interviewer: *yeah. Yeah, yeah, yeah.*

Frances: *I feel very stressed. I get really stressed sometimes. You get to a stage where you sit down and you cry, and you don't know what you're crying for.*

[Frances; 70s; tablets; diagnosed 40 years]

Frances' account reveals her fragile emotional health, and highlights sources of stress which were common to the narratives of Indigenous participants, such as premature deaths, worrying about children and grandchildren, and family disagreements and feuds.

Although stress featured prominently in the narratives of Indigenous participants, exposure to multiple stressors was not unique to their experience. Lorraine, who lived by herself but reported being visited regularly by her children, recalled the time when her daughter was on drugs and a close friend had died; she later describes the impact of that stressful period on her BSLs:

*Being upset sent it flying, yes, I know that. It's been over 10, 12, 14... it was gone 25, I think, when my friend died, and I... when she went, it took a lot... it took a lot out of me, you know...*

[Lorraine; 70s; tablets; diagnosed three years]

Peter, who has two adult sons living with him and his wife, reflects on the support he could expect to receive from his sons, and his account reveals some of the competing demands in his life, including having custody of one of his granddaughters:

*If I asked for moral support, I'd have my head beaten, I'd say. The oldest boy's an alcoholic. He can't have his daughter, because he's a violent alcoholic. And we've got custody of the other granddaughter for other various reasons... so... yeah. It's very hard to say anything.*

[Peter; 50s; tablets; diagnosed seven years]

Similarly, Patricia, who reported good glycaemic control despite struggling with her weight, recalls her previous attempts at dieting, and her account provides an insight into the personal crises she has faced in the last couple of years:

*I've always been told that I have to do something about losing weight. I was put on Optifast®<sup>27</sup> from the diabetic clinic at [tertiary hospital], and I lost 40 kilos. And then my partner passed away, so that was a bad year. And then I was broken into, and lost a lot of stuff, and got very little back from the insurance company. And so that brought me down and then mum had a stroke on top of that, and then it was the problems of trying to get her sorted out, strip her house and get rid of things, and rent the house out. And of course now she's blaming me for ripping her apart... ripping her life apart. I mean she's getting dementia, so all she can see is that I took her home away from her; I took everything and gave it away, that's what she thinks. So the last two and a half years have been pretty rough, so... yeah.*

[Patricia; 60s; insulin; diagnosed six years]

The experience of Diane, the youngest participant, provided an insight into the competing demands of caring for young children. Diane describes how she gets short-tempered with her eldest son, and her account highlights the stress she is under as a single mother, and the impact on her physical and mental health:

*I yell, and he gets scared, but it's the point that I've just had so much crap that I've been... it's been playing on my head, it's been playing on my body and I snap, like... I understand, but he doesn't, it's not his fault, I mean... he's six years old... but I mean he, most of the time saw me when I went through the whole injecting stage... 'I'm sorry mummy', he would give me a kiss on the belly or something like that, but he doesn't understand, and he doesn't have to, he's six years old. It's more the fact of ... I've got to keep in my mind, as well as everything else: don't snap at the children, don't snap at the children, because it's not fair on them, it really isn't, and I feel really bad because I don't always know why ... I stress a lot... I mean I thought of so many times going to the doctor and say 'give me something, because I'm stressed out to the max', I'm snapping at my children, it's not fair on them or me, or [the children's father]. Sometimes I'll just ring [the children's father] and say 'can you just come and get them?'*

[Diane; 20s; tablets; diagnosed one year]

Against the background of the multiple stressors present in most participants' lives, Rose's account revealed a specific source of stress which appeared to dominate her experience of disease, and, more broadly, her life: her husband Michael. An incident which took place at the start of Rose's interview provides an insight into the dynamics of her relationship with her husband, and their impact on Rose's stress levels. As we are about to begin the interview, we are interrupted by a phone call from Michael; when Rose returns, she quips:

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<sup>27</sup> Meal replacement diet program suitable for people with T2D.

*That's why my diabetes is full of stress.*

This early incident set the pace for the interview. The word-frequency analysis of the interview transcript reveals that 'stress' and 'Michael' were some of words most frequently used by Rose. As she reflects on how she copes with her disease, her account suggests that she perceives Michael as the main stressor in her life:

*Well, actually, it's not my diabetes, I have no problems with my diabetes, it's the... it's ... like, you know, when I get upset with Michael, and he's so rude, you know. He can be a very nasty man.*

[Rose; 60s; insulin; diagnosed 20 years]

Marko's account also unveiled high stress levels, although in his case the sources were of a different nature. Marko reported having been diagnosed with depression and during the interview it became apparent that there were multiple stressors which compounded his perception of having a poor quality of life. Neighbourhood safety concerns dominated a significant part of Marko's interview, as he reported that both he and his wife had been the victims of crime in several occasions. Marko comments:

*When you got diabetes and all those medications you get very stressed, you know... It's not an environment, you know, where you can do in peace and quiet. It is, uh... but it's everywhere like that today, they're violent people around you, and, uh... you know, they steal from you, they're harassing you if you don't... if you don't get off their way, you know, the push you off your way [laughs]. Yeah, you've got to watch yourself, and not to say anything. If you say anything to somebody they bump you on the head.*

Later in the interview, Marko makes a vivid remark which brings to the fore his high anxiety levels and his perception of his poor quality of life:

*Is very stressful, is very confusing and is... for old people, old people... live in fear, you got to be locked up like as a dog, or in a prison in your own house. If you don't do that, you don't survive, that what it is...*

[Marko; 70s; tablets; diagnosed 10 years]

Although the impact of living on fixed low incomes coloured the experience of disease of all participants, some faced severe financial difficulties which placed them under significant stress. This was the case of Jim and Rhonda, who reported being in 'financial chaos', a situation which had led them to seek the appointment of an administrator. Similarly, Martin provided an account which illustrated his financial

hardship, as he reported, for example, that his fridge was not working and he did not have enough money to repair it or buy a new one.

Participants' narratives revealed that being exposed to high stress levels impacted directly on self-management. Nicole reflects on the disruption to her self-management routine brought about by the instability of her household dynamics:

*Well, I thought I had this all down pat... right. And I had the booklets and everything, and I was writing them down, and the readings three times a day, and whatever... and then I got it all right, and then my whole lifestyle changed... It goes through stages, and the kids come back, and going here, there and everywhere, so the routine was interrupted, and then there was a lapse, and now I'm going to be facing all these challenges again after ten years...*

Later in the session, Nicole discusses further the challenges she faces, as she talks about the impact of having her adult sons living with her on her diet:

Nicole: *... between the food and the medications for me, and then now with the kids coming, two adult kids in the house, some of that food's going to have to go in my bedroom, because they're going to run out of food, they're going to eat mine. When they get their own money, they don't buy a lot of food*

Everybody: *Yeah...*

Nicole: *so... if I had those little snacks, well they're going to want the little snacks too, and it's not going to benefit them as much as it's going to benefit me. And then I have to go and put a whole wardrobe back in my bedroom and a pantry in my room.*

[Nicole; 50s; tablets; diagnosed 10 years]

Frances' comment illustrates the impact of stress on her diabetes self-management:

*Well, you pick at this and that, and eating your tucker and everything, stressed... you're getting wild inside yourself. We shouldn't be doing that. We should be resting in peace.*

[Frances; 70s; tablets; diagnosed 40 years]

The negative impact of stress on glucose levels was discussed during the non-Indigenous focus group, and led Anne to disclose experiencing suicidal ideation triggered by the demands of her complex medication regimen:

*You've done everything right, and your sugar levels... and you're thinking 'why are they so high?' and it's because you're stressing... I mean, I got to the point ... thank goodness my husband came home early from work, because I got my tablets and I thought 'will I take all this?'*

*my life will end up... And I was ready to take all my medication... because it gets on top of you. When you're taking so many tablets, so many injections... I've got a diary for all my medical appointments; and [staff member] from transport at the hospital she says, 'I don't know why you just don't move in here, you know [...] Monday to Friday, there's only Tuesday that you're not at the hospital'... Bloody hell, I'm here again, you know. And you get to a point sometimes where you don't seem to be getting any further forward... and I went and talked to the psychologist and I mean yeah, I'm fine now but that's how it gets you. And it just starts off with diabetes, and then it manifests into other things and what have you, and it's very hard to take it... yeah...*

[Anne; 50s; insulin; diagnosed 10 years]

Participants shared a common understanding of the importance of reducing their stress levels, and reported implementing strategies to reduce stress including going to church, listening to Christian tapes, meditation and visualisation techniques. Alison, who reported that both her daughter and husband had mental health issues, mentioned her daily meditation routine as part of her diabetes self-management. Alison hesitates at first – perhaps unsure about my reaction – and then describes her visualisation technique and, by doing so, reveals her understanding of health and wellness:

*Alison: I'm also... my husband and I both believe very much in... [hesitates] it might sound very strange, but we both believe in the visualisation of things, and I actually try every night, I always have a little... I do meditation, and I sit and I meditate. Every day I always focus on myself being perfectly healthy and being diabetes-free, so I suppose that's something I do every day.*

*Interviewer: that's very interesting. And tell me, when you do visualise and think of being 'perfectly healthy' as you just said, what do you think of? What's 'being healthy' for you?*

*Alison: uh... well, being healthy I suppose is being a lot slimmer than I am, losing a lot more weight, uh... being diabetes-free, being free of high blood pressure, and being a lot more active. I suppose those are the things that appeal to me.*

*Interviewer: and that's what you visualise?*

*Alison: yes, I try to visualise myself a lot slimmer, uh... and I try to visualise myself doing physical things that I'm not capable of doing now, you know, like rock climbing, swimming and other things that I loved to do, but can no longer do.*

[Alison; 50s; tablets; diagnosed eight years]

Similarly, Martin, who was filing for divorce at the time of the interview, talked about reading the Bible and meditating at a Buddhist centre to combat his high levels

of stress. Martin reported that the most important aspects of his self-management were: first, to reduce his stress levels; and second, to forgive his wife for her infidelity.

### ***The role of social networks***

Participants' narratives revealed that their social networks had the potential to influence their experience of disease and self-management positively or negatively. On the one hand, many participants reported obtaining practical and emotional support from their social networks, particularly from their families and friends. On the other hand, those same social networks could be a source of added stress and frustration, as many participants shared the perception that those around them did not understand what they were going through.

### **Social networks as support mechanisms**

Participants' accounts of their experience of living with and managing their diabetes revealed the important role of their social networks as sources of both emotional and practical support. As discussed previously in this chapter, most participants reported having a family history of diabetes, and they often identified family members with diabetes as an important source of practical and emotional support. Gail reflects on the importance of having family support:

Gail: *I'm very lucky though, I've got a very good back-up family*

Joan: *yeah.*

Interviewer: *is that important?*

Gail: *very important to have...*

Joan: *oh, yeah.*

Gail: *... family, to know where you're at and they can help you a lot, and sometimes we get naughty, and you've got to be talked to, I mean, I know I like fish and chips and my daughter says, 'well, it's full of fat, and it's no good'; because she's a health fanatic.*

[Gail; 70s; insulin; diagnosed 20 years. Joan; 70s; tablets; diagnosed five years]

Many participants reported receiving practical support from close family members and friends on specific aspects of self-management such as help with food shopping, meal preparation, and compliance with medication regimens. Close relatives with diabetes were also reported to be a source of advice and emotional support. Leah, a young Aboriginal mother of three who took part in the non-Indigenous focus group,



provides an account which sums up participants' views on the importance of this source of support. Leah talks about the advice she gets from her mother – also diabetic – and her comment reveals the central role her mother plays in her self-management:

*My mum is always my biggest support, because she says 'don't do this, don't do that, take your tablets, walk, exercise, ride a bike...' [...] Just listen to her; that's it. That's all I need.*

[Leah; 30s; tablets; diagnosed eight years]

Similarly, Anne, despite reporting being satisfied with the quality of care she receives from health professionals, reflects on the importance of having someone close to provide information and advice:

*I understand what's being said to me, but you can't... the information that is given... we're all individuals, and what works for one doesn't work for another. And if you've got other people in the family with diabetes, you listen to them, what they've gone through, what they did... and you can sort of tweak on the information. But when you know you just ... you've got nobody in your family, you've got nobody to talk to.*

[Anne; 50s; insulin; diagnosed 10 years]

Anne's comment on 'tweaking on the information' highlights her perception of the importance of combining structured information with more personal advice provided within a family or support group environment. Sheryl talks about a friend – also diabetic – with whom she goes to the swimming pool, and her account provides an insight into the emotional support as well as the practical advice she gets from this friendship:

*Sheryl: it's someone else who's going through it, you know. I mean she's worse than me, because she's got other health problems, like a pace-maker and everything, so she's sort of backwards and forwards from the doctor all the time, you know, and I pick up bits and pieces from her, yeah, so...*

*Interviewer: that's good.*

*Sheryl: but, uh... yeah, it helps you a lot, yeah... not only through diabetes but I think mind-wise too, you know, yeah.*

[Sheryl; 60s; diet; diagnosed one year]

## Lack of understanding from family and friends

Many participants reported that it was hard for other people to understand the impact of diabetes and accept the restrictions imposed on them by the self-management of their disease. Some participants talked about those around them not accepting or being in denial about their disease; Sheryl reflects on her husband's attitude towards her condition:

*I think he thinks I'm putting it on, you know.*

Later, Sheryl talks about the ritual of her evening tea and reveals a habit her husband has been unable to break, which illustrates his lack of acceptance of her condition:

*Mostly I'll have a cup of tea at night, but I use sugar things anyway. I haven't had sugar for years, but he'll always bring me a piece of cake or a biscuit at night, I don't know why because I always say 'no, I don't want a biscuit', you know, but he still can't, I mean, he still can't sort of accept just to come in with a cup of tea.*

[Sheryl; 60s; diet; diagnosed one year]

Similarly Lorraine, who reported recently having been diagnosed with angina, commented that her youngest son could not accept her poor health. Lorraine reflects:

*He doesn't like me going on this diabetes diet, he says 'you should eat more, mum, 'cause you're not eating enough'.*

Later, Lorraine recalls her son's reaction when she told him she had angina:

*He was here the other day, called in in the afternoon and he turns around and he says 'how are you feeling?' 'I'm feeling better', I said 'I got angina, we know what it is now'. 'Oh', he turns around and says, 'how long have you got that for?' 'As if it's something you're going to get and then go away. But it doesn't go away; it's there for a lifetime. Oh, you know, he doesn't pop in in the afternoon after work now, like in the last couple of days, because he just doesn't know what to do.*

[Lorraine; 70s; tablets; diagnosed three years]

Lorraine's account reveals how saddened she is by her son's reaction. Similarly, Alison, whose mother died of diabetes complications, reported that those closest to her had not fully accepted her diagnosis. Her voice fills with emotion as she reflects:

*Alison: I feel... my... my dad and my daughter in particular, even though my dad had his wife, you know, when she was diabetic, uh... being quite honest, they've not been as sympathetic about it as they could have, uh... and... that was quite hard, you know, it's quite hard for them to come to*

*terms with the fact that your mum and Alison is now not a hundred percent available, and not a hundred per cent well. They've... they've had quite a hard time with it, actually, yeah.*

Interviewer: *so how did you feel about their reaction?*

Alison: *uh... I tried to understand it, you know, I realise for my dad it was probably too much for him to cope with, you know; he watched his wife die, and he lost his wife young in life, uh... and... But part of me was hurt by it, you know; they are my family and they're the ones that love me the most and yet they still couldn't really accept it... it was a little hurtful, but I... I try not to dwell on that type of thing, I try to, you know, I think there's always a silver lining. You can always make a positive out of a negative. I try to be that way, you know... don't always achieve it.*

[Alison; 50s; tablets; diagnosed eight years]

Participants' experience of disease was also affected by the attitudes of friends and social networks more broadly. During the non-Indigenous interview, Anne comments on the upcoming Melbourne Cup<sup>28</sup>:

*It's hard when you've got friends... 'Are you coming to the Melbourne Cup lunch with us?' If I'm feeling OK, I'll be there. I can't make promises. I don't know how I'm going to feel on the 4<sup>th</sup> of November. And some of them, you know, they can't comprehend. 'Why can't you make that promise, that decision?' And you just can't. And it is difficult to try to get through to some people what you're living with, and you know you're not just living with one problem, you're living with another, and you get your good days and your bad days...*

[Anne; 50s; insulin; diagnosed 10 years]

Sheryl encapsulates the frustration shared by many participants at this lack of understanding as she reflects on what she finds the hardest about her diabetes:

*Everybody else thinking that it's something that you put on a shelf and get out again the next day.*

[Sheryl; 60s; diet; diagnosed one year]

Similarly, Rose's account revealed her frustration at other people's reactions, which compounded her stress levels and impacted negatively on her experience of living with diabetes. Rose reflects on people's lack of awareness and understanding as she recalls a visit to a friend's:

*Like, I'll go to my girlfriend's house, she'll be serving this... I've got no problem. She says, 'oh, I didn't prepare anything for you'. I say, 'no, I know what's good for me, I know what's not good for me, so I'll just pick*

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<sup>28</sup> Australia's major horse race event held on the first Tuesday of November.

*and choose what I want'. But she says, 'oh, aren't you going to eat this?' I say, 'no, I'm sorry, I wouldn't be having this'. 'Oh, oh, you're so fussy'. I say, 'please, try and understand', I say. 'You guys don't know what it is to have diabetes. But if you have a little bit of understanding, it will be good', I say. And that's what upsets me. People have no understanding. They think, oh, diabetics, you know, they just have to keep away from sweets. I say, no. It's wrong, I say, they should read magazines about diabetes, read about diabetes, get educated and then you'll know it, instead of making fun of people. So yeah, that... that upsets me a lot. I don't like that.*

[Rose; 60s; insulin; diagnosed 20 years]

Alison bravely broached a subject that she appeared to regard as a taboo: comparing diabetes with cancer in terms of community awareness and support. Note that Alison hesitates halfway through and clarifies her remarks to ensure that she is not misunderstood:

*I suppose, like, with family and also with people, certain people I find they don't really give much... much consideration to sometimes the state of my health. That's been frustrating, you know. So if you say to people like I'm diabetic, or... it's brushed aside as 'oh, that's nothing', whereas if someone was to say I've got... I'm not... [hesitates] Please, I'm not saying that diabetes is anything like cancer, I know they're totally different... but if I was to say I've got cancer, like my friend [...] currently has cancer, people immediately go 'oh, my gosh, what can I do to help you? Can I support you in some way?' But if you say you've got a long-term condition, it's like 'oh, it's just diabetes', you know, they brush it aside.*

[Alison; 50s; tablets; diagnosed eight years]

Finally, Tony's account provides an insight into a consequence of this perceived lack of understanding as he discloses that he hides his diabetes status:

*Tony: well... it's funny, but do you know I try and hide the fact that I'm... that I've got diabetes? Because there's a stigma uh... sort of with it that, you know, you don't exercise and that you got it from eating too many chocolates and uh... you've abused your body, you know. So, I don't tell anybody.*

Interviewer: *oh, I see.*

Tony: *you know?*

Interviewer: *uh-huh.*

*Tony: uh... I don't know whether that's right or not, or just being a macho thing or... you know, that I'm healthy, you know... I'm a guy and, you know, [...] there's nothing wrong with me. I used to hide the fact that I had had a by-pass operation because people... you know, whether they*

*feel sorry for you or what, or you don't want to think that... I'm a man and I don't get these things; I'm healthy...*

Interviewer: *uh-huh.*

Tony: *but, I look healthy, hey? [chuckles]*

[Tony; 50s; tablets; diagnosed 10 years]

Tony's account reveals his perception of the stigma associated with diabetes, and his last remarks shed light on his understanding of health and well-being and his notion of manhood, and how these impact on his experience of disease.

## **Conclusion**

Diabetes had a negative impact on participants' physical, emotional and psychological well-being: reports of fatigue were common, as were symptoms associated with hyperglycaemic and hypoglycaemic episodes, and mood swings. Participants' experience of diabetes as a family disease influenced their experience of diagnosis and their understanding of diabetes as a progressive disease, and shaped their fear of diabetes complications.

The social environment influenced participants' experience of disease. High stress levels were common and had a negative impact on participants' psychological well-being and their ability to cope with the demands of self-management; and there was evidence that social networks played a dual role, enabling or hindering self-management.



## **Chapter 9 – ‘Like a Drive-Away Service in a Garage’: The Experience of Medical Management**

In this chapter, I present the findings relating to participants’ experiences and perceptions of the medical care of their diabetes. The results presented in this chapter relate to the medical management aspect of the study’s first objective:

To explore the attitudes and experiences of disadvantaged persons living with T2D with respect to the medical management of their disease, and seeking access to healthcare services for the management of their disease.

And the study’s second objective:

To analyse participants’ perceptions of the quality of care they receive for their diabetes and how these perceptions are formed.

### **Self-reported access to healthcare services**

In this section, I present the results on participants’ experience of realised access to healthcare services for the medical management of diabetes. I include participants’ reports of medical care received within primary and specialist care settings, and reported access to diabetes self-management and education resources.

The analysis of the data on participants’ self-reported access to healthcare services for the medical management of their disease revealed a wide range of experiences that suggested a lack of a consistent model of care. As the sample comprised participants who reported regimens across the spectrum of diabetes management – insulin, oral hypoglycaemic agents, and diet-only management – a range of experiences of medical care was expected. However, participants’ accounts revealed a range of experiences even among those who reported a similar management regimen. In the context of this apparent inconsistent model of care, the subsample formed by clients of Derbarl Yerrigan Health Service Inc had a distinct experience of diabetes medical care, which I present separately.

## **Primary health care**

The findings on participants' reported access to healthcare services within a primary healthcare setting are presented here. Participants' reports of access to GPs and allied health professionals (AHPs) – dietitians, diabetes educators and podiatrists – are presented separately.

### **General practitioners**

Most participants reported accessing a GP regularly; however, their experiences varied greatly with regard to the reason for and the frequency of their visits. Similarly, their experiences also varied with regard to their reports of the frequency of tests and examinations performed by their GPs for the medical care of their diabetes.

Although most participants reported having regular access to a GP, two participants had not seen a GP for months, while Diane spoke of the access issues she faced. As participants in the focus group are invited to talk about their medical management, Diane is the first to speak, and her account reveals her frustration:

*That's the point, there is no-one to see, you don't have one... for me... one doctor in one place... you just... the moment you go to one doctor at one place, they move to a different place, and then you've got nobody. And then you want to go to see him, 'cause he could be, you know... I mean my doctor moved to Fremantle<sup>29</sup>, I can't go every time from here to Fremantle. Another doctor up here, they moved to Armadale<sup>30</sup>... I can't go to Armadale...*

Later in the session Diane adds that, as a result of her GP's move, she only gets to see him when the father of her children drives her to Fremantle. Diane comments on the frequency of her visits to her GP:

*It's not really on a regular basis because, I mean, I can't always get to see him, but it's 'regularish'.*

[Diane; 20s; tablets; diagnosed one year]

A desire for continuity of care was a common theme to participants' accounts, and participants generally reported having seen the same doctor for years, in some cases for up to thirty years. In this context, although most participants saw GPs who

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<sup>29</sup> Coastal city located 20 km south west of the CBD.

<sup>30</sup> Outer suburb located 28 km south east of the CBD.



practiced locally, some reported travelling to other suburbs to continue seeing the same doctor; Liz explains where her GP is located:

*Our doctor's in Wembley<sup>31</sup>, because we lived over there, so we've always stuck with him, and we go over there on a regular basis.*

Later, she adds:

*If we move from here, which we'll probably have to, because we've put our name down for Homeswest<sup>32</sup>, we could possibly be going down the Armadale area; so then, as much as we would like to stay with him, it depends financially on fuel and stuff like that, if we can afford it.*

[Liz; 60s; tablets; diagnosed four years]

Liz's account highlights the importance she and her husband Bill – also diabetic – place on seeing the same doctor, and the effort they make to maintain that continuity, but it also reveals the financial implications of their choice, and their need to balance priorities within their limited budgets.

Reported frequency of access to GPs varied from once every two or three weeks, to once every six months, and was influenced by the reason for the visit. Most participants reported visiting their GPs regularly to get their prescriptions for diabetes medications, and medications for other medical conditions. Frequency of access to GPs was also influenced by the development of diabetes complications, and by the treatment of or follow-up on existing co-morbidities, as some participants reported having recently undergone operations such as heart by-pass operations or hip replacements, and medical procedures such as the implant of a stent. Lorraine talks about her frequent visits to her GP, and her account reveals that she has recently suffered from a build-up of fluid in her lung and she has also had a diabetes-related ulcer:

*I caught a cold [...], and it went down... gave me a little bit of fluid on my lung. [...] Well, I was going every week for a while. Now, I go every fortnight. And I stay on that unless something goes wrong and I start going back weekly again. But... it just depends on just how things go for that [...]. When I did my leg, and it took me nearly two months, nearly three months to get rid of it [the ulcer], I was going every week, for a check-over.*

[Lorraine; 70s; tablets; diagnosed three years]

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<sup>31</sup> Inner suburb located eight km west of the CBD.

<sup>32</sup> State public housing authority.

Cecil reported having more frequent medical appointments because he had just been diagnosed with Crohn's disease, while a lesion in his pancreas and intense shoulder pain were being investigated. Similarly, Patricia, who reported suffering from lymphoedema in both legs and struggling with her weight, explains why she sees her GP every two or three weeks:

*Because she's got to keep an eye on my legs, and anything else, and she makes me get on the scales, and then she yells at me... in fun of course.*

[Patricia; 60s; insulin; diagnosed six years]

Lastly, participants' reports of the frequency of diabetes-related blood tests were also varied, with some reporting having blood tests as frequently as every eight weeks, while others reported having them once a year. However, the majority of participants reported having six-monthly blood tests for the medical management of their diabetes, which is consistent with the minimum recommended by the Australian *Diabetes Management in General Practice* guidelines (Diabetes Australia 2010).

### **Allied health professionals**

Overall, evidence of access to AHPs was limited. Participants' self-reported access to dietitians and diabetes educators was mixed, although the majority reported having seen one at some stage since their diagnosis. For most participants who reported having seen a dietitian, access was experienced as a one-off session as part of a structured diabetes education course attended following their diagnosis; however, a limited number of participants spoke of having accessed dietitians or diabetes educators under other circumstances: two participants reported having seen a dietitian as part of a General Practice Management Plan (GPMP) coordinated by their GP, while some reported having seen dietitians at either Royal Perth Hospital (RPH) or Sir Charles Gairdner Hospital (SCGH), the main tertiary hospitals in the Perth metropolitan area, either in the context of specialist outpatient care, or as inpatients.

Despite the importance of foot care in diabetes management, evidence of access to podiatrists was very limited, with the majority of participants reporting not accessing podiatry services regularly, if at all. Some participants said they had never seen a podiatrist – including insulin-dependent participants who had lived with diabetes for

up to twenty years – while others reported having had one-off visits in the past, for example while in hospital.

## **Specialist care**

Participants' self-reported access to specialist services is discussed here, and includes reports of access to diabetes specialists, and ophthalmologists and opticians.

### **Diabetes specialists**

Most insulin-dependent participants reported seeing a diabetes specialist regularly. Those who saw a diabetes specialist reported accessing the Diabetes Clinics at either RPH or SCGH six-monthly or yearly as public patients, and having blood tests as part of their routine visit. Rose provides a typical description of a visit to a specialist:

*He's the diabetic specialist, he sees to us, and, like I said, you know, they just put us on the table, check up fingers, toes, and kidney, and whatever they got to check, and it's all... you're talking and he's doing all the writing, and then if he has to reduce your tablets, he'll reduce it, or he has to increase it, he'll increase it, and that's about it. We go... once, yeah, once a year to see him.*

[Rose; 60s; insulin; diagnosed 20 years]

Bridget and Cecil reported being followed by their GP only and never having seen a diabetes specialist; however, Cecil, who had been on insulin for only two weeks at the time of the interview, explains why he believes his GP will refer him to a specialist:

*Because he wants my sugar levels down to a very, very low six, and I find it hard to get it down there, and, you know, so, for about three to four months he kept saying, 'if you don't bring it down properly, I'm going to give you insulin and I'll put you on insulin, blah, blah, blah, blah, blah'. And then that's it, he goes, 'sorry, you're going on insulin', and that was it. Now I find out it's not as high, but it's not as low as it should be.*

[Cecil; 50s; insulin; diagnosed five years]

Martin, a non-insulin dependent diabetic whose account revealed a high degree of social isolation, was the only participant who spoke of having seen a private specialist in the past. He reported that his specialist bulk-billed for his consultation, and that he had stopped seeing him following his retirement from practice.

Two participants, Alison and Jim, both on oral hypoglycaemic agents, reported accessing a specialist clinic at one of the main tertiary hospitals as they were taking

part in a clinical trial for the drug Byetta®<sup>33</sup>. Alison reported having been on the trial for six months when the interview took place, and seeing a specialist every three months; while Jim said he no longer saw a specialist to follow up on his progress, although he was still required to access the outpatient clinic to get his prescription for the injections.

### **Opticians and ophthalmologists**

There was strong evidence of regular access to opticians and ophthalmologists. Most participants reported having eye problems, either cataracts – which occur prematurely in people with diabetes – or a tendency to develop glaucoma. Many reported having had a cataract removed in the past, in either one or both eyes, and some reported having a cataract operation scheduled in the weeks following the interview. Moreover, one participant spoke of recently having had his driving licence withdrawn because he had developed glaucoma.

Participants who did not report a history of cataract or glaucoma tended to have their eyes checked by an optician, usually once every two years, while those who had a history of an ophthalmological condition tended to have their eyes checked by an ophthalmologist at outpatient clinics at either RPH or SCGH, usually yearly, although one participant reported having her eyes tested six-monthly.

### ***Access to self-management education and resources***

Results on reported access to self-management education and resources within and outside the healthcare setting are presented here.

#### **Self-management education and resources within the healthcare setting**

Participants' experiences of access to diabetes self-management education (DSME) varied; however, they had one common theme: access was typically limited to a one-off event. For most participants, this event took place in the weeks following their diagnosis, and was experienced either as a community-based structured diabetes education course, or as a counselling session provided during the course of a regular consultation with their GP.

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<sup>33</sup> Injectable prescription medicine used with a diet and exercise program that may improve glucose levels control in people diagnosed with T2D.

Approximately half of the sample reported having attended a community-based DSME course following their diagnosis. Most participants who accessed these structured self-management courses reported having been referred to a one-off session run by either Osborne Park Hospital – the closest community hospital to the sampling area – or Joondalup Health Campus – a tertiary hospital located in the north metropolitan area. Two participants reported having been referred to a dietician following their diagnosis as part of a GPMP, while another reported having attended a course run by Diabetes WA; these participants had a distinct experience, as they reported attending five or six education sessions, rather than just one.

The rest of the sample reported having received information on self-management from their GPs, typically limited to advice on diet, exercise, and how to recognise and manage a hypoglycaemic episode or ‘hypo’. Liz’s answer when asked about what information she was given when she was diagnosed sums up this experience:

*Basically what to eat, to be aware of hypos and carry like the jelly beans or whatever sweet with you. Uh... that’s basically it, I think.*

[Liz; 60s; tablets; diagnosed four years]

Participants who reported their GP as the main source of information on self-management also spoke of receiving written resources from them. Lorraine talked about the information she received following her diagnosis; when asked if she had been referred to a dietician, Lorraine produces a booklet entitled *The Heart Care* – which contains one section on diabetes – and comments:

*No, no, the doctor just gave me [this booklet]. And that’s... that’s the book I went by. He turned around and said ‘if we continue just doing that that’s in the back of the book’. I read all of it, and it’s got the GIs and things like that. And I just went by that.*

Asked if she had received any further information since that day, Lorraine answers:

*No. Just that book, that’s all I’ve had to go by.*

[Lorraine; 70s; tablets; diagnosed three years]

When Bridget and Cecil talked about the information they had received following their diagnosis, Bridget reported having been referred to six sessions with a dietician, however Cecil, who was diagnosed a year later than his wife and sees the same GP, said he had never been to any DSME course, which points to either the inconsistency

of the model of care received or perhaps the inconsistency of their reporting. Cecil and Bridget spoke of having received advice from their chemist, as Bridget recalls:

*Our chemist down the road actually helped a lot when I first was diagnosed. He was really good. [...] He actually sat with me when I had my first needle, didn't he?*

Later in the interview, an exchange between Bridget and Cecil reveals the extent of the information they reportedly had received since their respective diagnoses. When asked if they have received any further information over the years, they engage in the following conversation:

Bridget: *none, really.*

Cecil: *oh, we received a little bit from the Diabetes Australia, what avenues we've got, how to get stuff, and they sent us a little, mini booklet with recipes.*

Bridget: *oh yeah.*

Cecil: *and I think we had somebody over the phone or somebody came over here...*

Bridget: *no, over the phone.*

Cecil: *over the phone, you know, sort of telling us we need this, we need that, and they gave us a brochure on what some of the stuff, you know, the back-up stuff, costs... and that's about all information we've had. We haven't had anyone come and sit and talk to us, to, you know, give us any guidance.*

[Bridget; 50s; insulin; diagnosed six years. Cecil; 50s; insulin; diagnosed five years]

Similarly, Jim and Rhonda reported having received very limited information from their GP. Jim, who was diagnosed by the same GP five years earlier than his wife, said that Rhonda had received 'nil' information from the GP at the time of her diagnosis. Jim recalls what the GP had said to him during the consultation:

*We were both her patients, and generally she [GP] said... she said to me, 'you can show Rhonda more than I can'.*

[Jim; 60s; tablets; diagnosed eight years]

Rhonda also commented on this consultation. When asked if she had received any information, she recalls:

*No. She just said, 'oh, you've got sugar diabetes'; that's all.*

[Rhonda; 60s; tablet; diagnosed three years]

Later in the interview, Jim disclosed that it was only through the support of his sister-in-law – a nurse at a tertiary hospital – that he had been referred to a diabetes self-management course.

### **Other sources**

Participants reported accessing information on self-management through other means, and cited family members, work and social networks, Diabetes WA, books and the Internet as sources of information. Reported access to self-management resources through other sources appeared to be related to participants' self-reported level of satisfaction with the quality of care received. Thus, participants who reported receiving little information from their GPs and a general lack of satisfaction with the quality of their medical care were more likely to report accessing alternative sources of information, while those who reported being satisfied with their medical care typically reported less access to these sources.

Several participants mentioned the Internet as a source of information unprompted; their accounts were mixed, and highlighted the issue of potential misinformation. At one end of the scale, Bridget's account reveals her effective use of the Internet to search for specific information that is useful and relevant to her – Bridget and Cecil's was the only home where I observed a computer, and their narratives revealed that both used the Internet regularly. When asked whether she was referred to a DSME course after her diagnosis, the following exchange ensues:

*Bridget: when I was first diagnosed, yes. I went to about six sessions with a dietician.*

*Interviewer: alright, yeah, yeah. Was that helpful?*

*Bridget: yeah, it was actually, it was pretty good. But do you know what I find more helpful? The Internet. [...] I find the Internet's a lot better. You can look up recipes; you can go to Diabetes Australia and look up all the recipes and that.*

[Bridget; 50s; insulin; diagnosed six years]

Other participants' narratives, however, highlighted a negative side to the use of the Internet as a source of information. Alison recalls how she attempted to search for information on GI following her diagnosis, and her account suggests that the experience left her feeling frustrated and disempowered:

*I do remember at the time, I said, oh, I'll look it up on the Internet. Well, we tried like... I don't use a computer, but my husband does, uh... we tried to find information about GI, and the only thing we could find was, 'oh, go and buy this book', and we couldn't get it from the library, and some of them were very expensive, and I couldn't afford them, so I really was... I felt like I was floundering in the dark.*

[Alison; 50s; tablets; diagnosed nine years]

Furthermore, Gail's account highlights the potential for the Internet to become a source of information overload and misinformation. When discussing her sources of information, Gail mentions her friends, later adding:

*I've got a son-in-law who gets it off the Internet. [...] He types up 'diabetes' and you get pages and pages to read.*

[Gail; 70s; insulin; diagnosed 20 years]

Some participants reported taking a personal interest in finding out more about their disease, reading books on diabetes, and following up on research developments on diabetes. Diet books such as the *Atkins Diet*<sup>TM</sup> or the *CSIRO Diet*<sup>34</sup> were also cited as sources of information. Lee, who was diagnosed with hyperglycaemia and reported having received no information about her condition from her GP, talks about her sources of information:

*I was in the department, the book department, and I'm very curious as a person anyway. I [...] accessed the CSIRO things. I looked up what hyperglycaemic is on the Internet, because you do when you find out that you have these things. But I've not had anything else other than that [...] information.*

[Lee; 60s; tablets; diagnosed with hyperglycaemia one year]

Peter, who mentioned the *Atkins Diet*<sup>TM</sup> several times during the interview, acknowledges the limitations of the information provided by books as he reflects:

*I got the Atkins book out, and I learned that potatoes are bad, pastas are bad and a few other things, but it still doesn't... I still need to talk to a proper diabetic dietician to know what I should eat and what I shouldn't eat. And get, you know, a diet plan going.*

[Peter; 50s; tablets; diagnosed seven years]

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<sup>34</sup> Diet based on high protein, low carbohydrate intake published by Australia's Commonwealth Scientific and Research Organisation (CSIRO).



## ***Model of care provided by Derbarl Yerrigan Health Service Inc***

As discussed elsewhere (see Chapter 4), the majority of Indigenous participants who took part in the study were clients of Derbarl Yerrigan Health Service Inc (Derbarl Yerrigan), an Aboriginal community-controlled organisation providing healthcare and Home and Community Care (HACC) services to Aboriginal clients in the Perth metropolitan area.

Based on participants' self-reports, the diabetes model of care delivered by Derbarl Yerrigan was characterised by the following elements: clinical care was delivered in a community health clinic setting, with easily accessible GPs, nurses, and HACC workers; clients' medications were the object of periodic review; and a coordinated, client-oriented approach guided health care delivery.

### **Access to medical services**

Derbarl Yerrigan clients reported seeing their GP regularly, monthly or as often as once a week, for the management of their diabetes. Generally, participants' accounts revealed that they had ready access to clinical services, with one client reporting being able to see her GP or a nurse even without prior appointment, and another reporting having her BSLs tested at the clinic once a week. All Derbarl Yerrigan clients reported having three-monthly check-ups, including a blood test performed on site, and a medication review.

Derbarl Yerrigan clients spoke of being picked up from home and driven to their medical appointments, and this travel arrangement included regular visits to their GP at the Mirrabooka clinic, podiatry appointments at the Derbarl Yerrigan East Perth clinic, and specialist appointments at RPH and SCGH.

Most Derbarl Yerrigan clients reported seeing a podiatrist regularly at the Derbarl Yerrigan East Perth clinic – some every month, some every eight weeks; and access to physiotherapists – barely mentioned by the rest of the sample – was also reported. While discussing quality of life issues during the focus group, Rachael mentioned seeing a physiotherapist; this prompted an exchange among participants which suggests that it was something they all had experienced and found beneficial:

Rachael: *physios do make you feel good.*

All participants: *yeah, yeah.*

Nicole: *and the physio knows what our bodies can handle, you don't have to do star jumps or anything like that. [...]*

Renee: *you need to be pampered.*

[Rachael; 60s; insulin; diagnosed 20 years. Nicole; 50s; tablets; diagnosed 10 years. Renee; 50s; dialysis; diagnosed 20 years]

### **Medication review and delivery**

Derbarl Yerrigan clients reported having a Home Medication Review (HMR) as part of their three-monthly diabetes medical management. They typically mentioned the HMR unprompted when discussing their medical care, which suggests they perceived this review as an important aspect of their medical management. Generally, Derbarl Yerrigan clients showed a high level of awareness about the program and its purpose, which was not shared by the rest of the sample.

Derbarl Yerrigan clients also reported having their medication sorted in *Webster-paks*® at no cost, and having their medication and insulin delivered at home. Gail explains how she gets her insulin delivered, and her comment highlights the flexibility of the model of care provided by Derbarl Yerrigan and its client-oriented approach:

*I've got to give her [HACC worker] a couple of days warning that I'm running down and then they arrange that and they bring it out; and I keep it in the fridge and it lasts.*

[Gail; 70s; insulin; diagnosed 20 years]

### **Comprehensive, tailored healthcare services**

The analysis of Derbarl Yerrigan clients' accounts of their diabetes medical care suggested that Derbarl Yerrigan provided comprehensive, coordinated, client-oriented healthcare services to its clients. During the conduct of the focus group and interviews held at Derbarl Yerrigan, I had the opportunity to observe the interaction between clients and staff members, and noticed that all clients were well known to staff, and were given individual, tailored attention.

Clients reported receiving regular check-up telephone calls by HACC workers, and they also spoke of being contacted whenever they were due for a medical appointment. In addition, they reported that their specialist appointments at RPH and

SCGH were coordinated by Derbarl Yerrigan, and they thought there was good communication between their GP and their specialists. Similarly to the rest of the sample, most Derbarl Yerrigan clients reported having their eyes checked regularly by an ophthalmologist at either RPH or SCGH.

An example of this coordinated, holistic approach to health care provision is provided by the experience of Nicole, a participant whose account revealed very poor glucose control and very poor self-efficacy with regard to her diet and alcohol intake. As participants talked about their diets, Nicole reported having to stretch her limited budget to have enough food for her family, adding that her GP had put her *Meals on Wheels* to ensure she had a balanced diet. A comment made by Renee sums up Derbarl Yerrigan clients' experience of their medical care:

*Yeah, they do a lot for people here.*

[Renee; 50s; dialysis; diagnosed 20 years]

### ***Summary of the experiences of the models of care for diabetes***

A summary of the diabetes models of care to which participants reported being exposed is presented here, including the mainstream model of care experienced by the majority of participants, and the distinct model of care experienced by Derbarl Yerrigan clients.

Figure 9.1 highlights the complexity of the diabetes model of care, and shows the referral pathways and cost implications. Most participants reported regular access to healthcare services that did not have any cost implications, that is, services that were bulk-billed by Medicare or were arranged under a GPMP. When out-of-pocket expenses were likely to be incurred, evidence of access to services was significantly reduced (services showing limited evidence of access are highlighted in red).

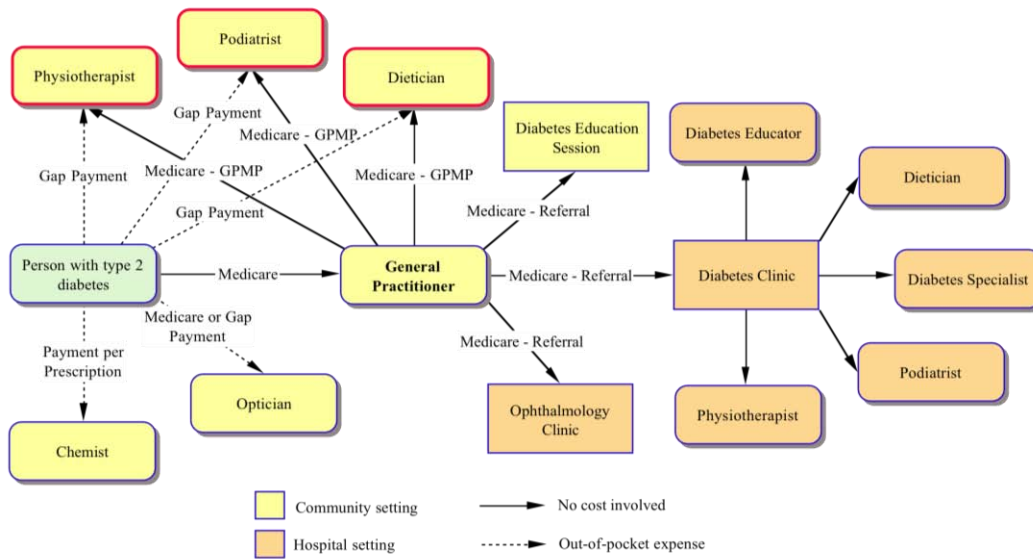


Figure 9.1: Participants' experience of the model of care for diabetes

Figure 9.2 provides an overview of the model of care provided by Derbarl Yerrigan to clients diagnosed with diabetes. Derbarl Yerrigan clients reported being exposed to a model of care which was less complex and more easily accessible, and which also suggested good coordination between specialists and GPs. In contrast with the experience of the rest of the sample, none of the services accessed had any cost implication, and, in addition, Derbarl Yerrigan worked directly with chemists and reviewed their clients' medication schedules regularly.

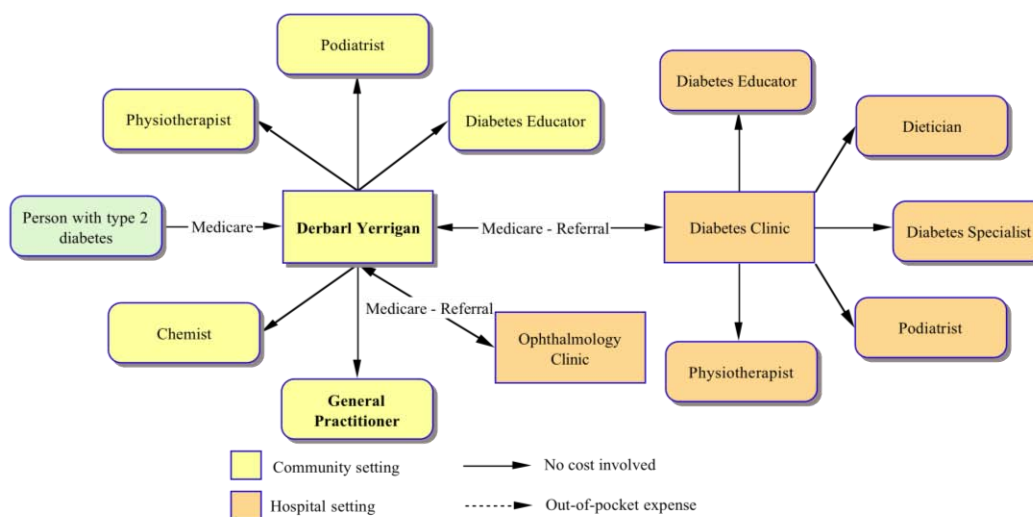


Figure 9.2: Derbarl Yerrigan clients' experience of the model of care for diabetes

## **Attitudes towards seeking access to healthcare services**

As discussed earlier, study participants reported a range of experiences of medical management; these experiences need to be understood in the context of their attitudes towards seeking access to healthcare services. Attitudes towards healthcare services generally are likely to influence attitudes towards seeking access to specific services for the management of diabetes. Furthermore, experiences of instances of access to healthcare services in general and diabetes-specific services have the potential to influence, either positive or negatively, future healthcare-seeking behaviour.

Participants' narratives revealed four factors influencing their healthcare-seeking behaviour: perceived need for healthcare services; impact of a previous negative experience of health care; information and awareness of available services; and cost as a barrier to access.

### ***Perceived need for healthcare services***

Participants' perceived need for healthcare services varied greatly depending on the type of service. Participants perceived eye tests as a high priority, and most were aware of the long-term impact of diabetes on ocular health and the potential for diabetes-related complications. When asked what health professionals they saw other than their GPs, most participants mentioned opticians or ophthalmologists first, often emphasising that they complied with doctors' recommendations of having their eyes tested at least every two years. As Lorraine talks about her cataract operations, she reveals her understanding of the potential for complications and reflects participants' common belief of the importance of regular eye tests:

*I had the first one done before I had the sugar, but the second one I had when I had the sugar. And he turns around over there at the surgery, and checks for fluids and extra fluids and things like that, because they know the sugar, I have the sugar diabetes, and it's got to be done. And I go, at the moment, I've been going every six months, 'cause everything's real good. But he said, 'if you get any sort of blurring or anything like that, you ring and tell them you've got it, and they make you an appointment straight away, there and then'.*

[Lorraine; 70s; tablets; diagnosed three years]

Participants' accounts revealed that their attitudes towards the need to seek the advice of dietitians were mixed and were influenced by their reported experience of overall self-management. Participants who reported stable glucose levels tended to report no or little need to see a dietitian, citing as a reason that they already ate a 'healthy diet'. Liz articulates this view as she comments on the reason why she and her husband Bill have never seen a dietitian:

*We didn't eat a lot of fatty food, we don't have takeaways, or very rarely would we have takeaways. Takeaway for me would probably be a cooked chicken, something like that that we can easily get for a meal, and if we have chips they're just put in the oven to cook, but not in fat or anything like that.*

[Liz; 60s; tablets; diagnosed four years]

Similarly, when asked whether she has ever seen a dietitian, Rose – who later in the interview acknowledged having had a bad experience with a dietitian in the past – comments:

*To me, I don't know, maybe I'm not thinking straight... To me, I know how to control my diabetes, so I think I'm doing the right thing, so I don't need a dietitian, right? I could be wrong.*

[Rose; 60s; insulin; diagnosed 20 years]

Participants who reported poor glycaemic control and whose accounts revealed lower levels of self-efficacy with regard to their diet were more likely to report the need to see a dietitian, as they generally felt that they were lacking dietary advice. Participants' accounts revealed that they relied on their GP to refer them to a dietitian; thus, if their GP did not act upon their request, they felt powerless to act on their perceived need. The feeling of frustration at not being able to access dietary advice became one of the main features of Peter's interview; he reflects on his struggle with his diet, and his comment reveals his powerlessness at his GP's lack of action:

*Peter: He [my GP] seems to think that I can manage it. I really think I need to see a diabetes dietitian so I know what I should eat and what I shouldn't eat.*

*Interviewer: so you've made that request to your GP?*

*Peter: I've made that request a thousand times and he's refused, so it hasn't helped my diet at all, so...*

[Peter; 50s; tablets; diagnosed seven years]

Patricia's account, on the other hand, reflects her awareness of the resources that are available to her. Patricia is on insulin and reported struggling with her weight; she talked about being put on the diet *Optifast*® by her diabetes specialist at the Diabetes Clinic of one of the main tertiary hospitals. Patricia recalls:

*I had seen the dietician a couple of times before I went on the Optifast®. Then they said a couple of times I should go back, and I said well I'm trying to get back onto the Optifast®, so I'll go back on the Optifast® so I'm not wasting her time and my time, but er... If I don't get back on the Optifast® and stay on it in the next couple of weeks, when I go in for my next appointment I will go to the dietician.*

[Patricia; 60s; insulin; diagnosed six years]

Perceived need for podiatrists was generally low among participants, and it was influenced by participants' low level of awareness of the importance of the care of their feet. Many participants reported not feeling the need to go to a podiatrist, as their feet were 'OK' and they were being careful enough. Paul, a participant whose account demonstrated a high level of self-discipline, revealed his scepticism about podiatrists; when asked whether he sees one, Paul quips:

*I can't see why a podiatrist... and the doctor says too... but a podiatrist can't do an awful lot for you, unless you've got ingrown toenails, buckled feet or something like that.*

[Paul; 80s; diet; diagnosed 18 months]

Participants' accounts revealed that most perceived podiatry services as a pedicure; this was a common perception even for participants who reported going to the podiatrist regularly. Peter's comment reflects this view when he describes what her podiatrist does:

*She basically cuts the dead skin off, prunes the toenails, and gives a bit of a buff.*

[Peter; 50s; tablets; diagnosed seven years]

Few participants demonstrated an understanding of other important aspects of diabetic podiatry, such as checking for reduced circulation or sensation, and assessing any mechanical instability of the foot. Lorraine, one of the few participants who reported having private health insurance, spoke of going to the podiatrist regularly. She recalls one of her visits, and her account demonstrates a high level of awareness of the importance of foot care, which sets her apart from other participants:

*And she turns around and says 'you wear your slippers in the house, Mrs [...]?' 'Yes.' She turns around and says, 'now you're sure you do?' 'Yes, I sure do'. And she says 'that's alright'. Then she massages it, and then she just makes sure that the pulse... the blood is circulating. And then she puts some cream on and massages it all for me and everything and checks me up every time I go.*

[Lorraine; 70s; tablets; diagnosed three years]

### ***Impact of previous negative experiences of health care***

Participants' healthcare-seeking behaviour was also influenced by previous negative experiences of health care, including primary and hospital care. Most reports of negative episodes of care in a general practice setting related to receiving very little or no advice from GPs; for some, however, negative experiences of care included the misdiagnosis of a health condition. Michael, a participant who reported holding an ambivalent view of the whole healthcare system, said he had recently had a shunt implanted to alleviate a build-up of fluid in his brain. Michael recalls his GP's initial reaction to his symptoms and how he only got diagnosed as a result of his wife's insistence on having an MRI<sup>35</sup>:

*And the best joke was, I kept falling all the time in the shops and taken to emergency. And when I go to him he says, 'oh, no, it's your sugar levels'. It wasn't that. And my wife is the one that says, 'can I get an MRI?' And we went to the MRI and they found fluid in the brain.*

[Michael; 60s; insulin; diagnosed 15 years]

Although participants generally valued continuity of care, two participants spoke of having changed their doctor because they thought their GPs had become 'lax' and uninterested in their condition, while a further two reported having stopped going to the doctor altogether because of their negative experiences. Martin's narrative provides an insight into the potential for complete disruption of the medical management of diabetes triggered by negative experiences. Martin, who is separated from his wife and is on treatment for depression, reported not having seen a GP regularly for the last three years, after having tried several doctors. He admitted to not following up on referrals for blood glucose tests because he 'didn't get a feel for the person', which meant that his diabetes had not been checked for months. Martin recalled one specific episode when he had gone to a doctor with a stomach

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<sup>35</sup> Magnetic Resonance Imaging: medical imaging technique used to diagnose conditions that affect soft tissue.



complaint, and the doctor had recommended an X-Ray; his voice as he recalled this incident revealed his incredulity, as he wondered why an X-Ray was ordered instead of an ultrasound, as would have been appropriate in his view. Martin's recollection of this episode is significant because despite the fact that it was not diabetes-related, it resulted in him not going back to that GP and losing an opportunity to establish the foundations for the regular medical monitoring of his condition.

Similarly, Lee reported being in 'a kind of limbo' since her GP of many years had retired, which resulted in her BSLs having gone unchecked for months. Lee admitted to being 'a little bit sceptical' about the medical profession and not having addressed the issue of finding another GP to oversee her condition.

Alison, who disclosed that her mother had died as a consequence of a medical negligence, spoke of regularly seeking a second opinion from a different GP. This strategy points to an inherent lack of trust in doctors, as Alison herself reveals:

*Because of the experiences my mother had, I always go to another doctor occasionally to get another opinion. My mother's care was very poor, and because of that she died, and I don't... I don't stick exclusively with one doctor anymore. Every... at least a couple of times every year, I always go to another surgery, and see a totally different doctor to get a different perspective on it. I'm not sure whether the doctors like that, but that's how I feel. I need to do that.*

[Alison; 50s; tablets; diagnosed nine years]

Participants' accounts also included several instances of negative experiences related to dieticians or diabetes educators. Michael and Rose both reported negative experiences with dieticians in their separate interviews. Rose's account reveals the underlying cultural factors that shaped her experience:

*She was good at first, but after she started to control [...], because I kept telling her, I said 'look, [my problem with my diabetes] is not because I'm eating the wrong food or doing the wrong things, it's the stress', I said, 'with, you know, I've got my mum living with me'. 'Oh, you bloody Asians, you live with your parents; they should be living out alone'. I said 'that's up to us, you're a dietician, you know'. And I said, hmm-mm, not my cup of tea, I said, you know, so I said... I said 'I know it's hard, but my mum is all alone', I said, 'and I haven't got my dad anymore, so I feel that, you know, the way we were brought up in our country, we look after our parents until it's time for them to go'. And I said, I said to Michael, 'I don't like this lady', I said. A couple of people had problems; she's not there anymore.*

[Rose; 50s; insulin; diagnosed 20 years]

Similarly, Alison recalls her experience when she was referred to the Endocrinology Department at one of the main tertiary hospitals; her emotive account reveals how deeply affected she still is by this incident:

*To be perfectly honest I was so badly treated by them, and they were so rude to me, I didn't go back [...] [sighs]. Well, essentially I was told that I'm lying to them, that because I weigh this... I'm heavy... 'you must be getting the calories somehow, you must be lying to us, and I don't believe what you're saying, that is just... you have to be getting the calories in there somehow'. And there was another incident with, I think, uh... I don't remember if it was a dietician, or whether it was the... it wasn't the endocrinologist himself, he was actually rather a nice man, one of the support people essentially said to me 'get your fat [...] together, and get your fat arse out of here', and so I didn't go back. [...] It was rather... it was rather upsetting. I... to be honest, at the time, I felt like hitting the person, but I wouldn't do that. It was simply... I didn't... I didn't respond at all actually; I just simply walked out, and I didn't go back. [...] No, I never went back to that particular department, I just thought... I... I never went back to the dietician... I thought I'm not going to be spoken to like that, I'm... twice that young woman's age and, you know, she's... yes, she's a very slender lady, she has a perfect figure and everything, but, just because she has that doesn't give her the right to treat me in that way.*

[Alison; 50s; tablets; diagnosed nine years]

Alison's experience is representative of that of participants who reported having weight problems, who often spoke of feeling confronted, misunderstood and judged by health professionals on the grounds of their physical appearance.

Participants' reports of negative experiences also included episodes of hospital care which influenced their healthcare-seeking behaviours. Michael talked about his recent experience at the emergency department where he was taken after collapsing in the street; he revealed that he had discharged himself from hospital, adding:

*They didn't do anything to me, nothing.*

[Michael; 60s; insulin; diagnosed 15 years]

Similarly, Peter, who reported having a history of heart disease and a back injury, talked about discharging himself from his local hospital following a cardiac episode that led him to the emergency department. His emotive account revealed that he was still shaken by the incident – which had happened a few days before the interview – and he admitted that he was considering lodging a formal complaint. Peter recalls the incident:

*I told them I had back problems so they left me sitting in a bed with the back up. Now, the bottom of my back... yeah, a lot of agony. [...] And after being there until half past five, and getting nowhere with 'em, all I had is three cups of water. I went cracking... the shits, so to speak. And I took the drips off, the patches off. And they all came out 'what are you doing that for?' I said 'I told you, you can't get me in a comfortable bed... I'm leaving'. [...] I walked out. I won't go back there.*

[Peter; 50s; tablets; diagnosed seven years]

## **Information and awareness**

A common theme across participants' narratives was the limited knowledge of the recommended model of care for the management of diabetes. Participants' accounts showed limited awareness of the importance of certain aspects of their management, in particular the care of their feet, and, in general, they had very little information on the healthcare services and community-based resources that were available to them.

Most participants were unaware of the existence of General Practice Management Plans (GPMPs). Furthermore, participants who had accessed AHPs as part of a management plan had limited knowledge about the conditions attached to the plans, including how often they could be set up, the health professionals they could access, and how many visits a year they were entitled to under these plans. Tony's tentative explanation is representative of this limited understanding of the purpose of GPMPs:

*[My GP] said that he was going to put me into one of these... I don't know what they call it, like... somebody could manage... 'cause my diabetes is always up, very high, uh... you know, to help me... you know... try and, you know, with diet and different things to get me on the right... but it hasn't happened as of yet.*

[Tony; 50s; tablets; diagnosed 10 years]

Lee, a participant who reported not having seen a GP for months, provides an account which illustrates her total lack of information on available services and resources:

*I do know that there probably are wonderful clinics close by, but I don't... I'm not aware of them and or if there's anything specific for diabetes. I don't know that information. There's not much on the Internet about it, other than uh... I tried to find out as much as... about hyperglycaemia and there's not much there, other than to take uh Metformin and restrict your sugars and uh... there's not a whole lot of other information.*

[Lee; 60s; tablets; diagnosed with hyperglycaemia one year]

Alison reflects on how she experiences this lack of information:

*But uh... I just... I kind of wish that... I'm not sure whether it's because of our area or whether it's the fact, you know, that I'm a Medicare patient, I'm not sure, but I do feel that uh... there's not really enough information about what services are actually available to you, and if... if they are available, well, you seem to have to fight tooth and nail to get them, and I do feel that that's quite unfair.*

[Alison; 50s; tablets; diagnosed eight years]

Alison's comment suggests that she feels discriminated against, and she perceives this discrimination to be based on her income and the place where she lives. This observation is consistent with Alison's whole narrative, as the issue of discrimination on the grounds of SES permeated her interview, and appeared to shape her experience of disease.

Furthermore, participants reported no awareness of the existence of a diabetes support group in their area, with two exceptions: Christine, who took part in the non-Indigenous focus group and who reported being part of a support group based in a neighbouring suburb; and Sheryl, who reported having considered joining a support group when she was first diagnosed. As she reflects on whom she would turn to if she needed more information, Sheryl's account reveals her awareness of the existence of the support group:

*Sheryl: well, I'd go through the doctor first, 'cause sometimes he can refer you to someone, or he can just say where there's a group, you know. 'Cause I remember, there's a couple of things... a group in Mirrabooka at one stage, I think it's happening at the library there, somewhere...*

*Interviewer: yes, I know where you mean, there's a support group.*

*Sheryl: that's when I first started, I thought about going there, yeah, but, uh... but I've got like a cousin, she's pretty bad, and this one I go swimming with relies on insulin, so, I sort of pick up things from them anyway, yeah...*

[Sheryl; 60s; diet; diagnosed one year]

In her comments, Sheryl refers to the local diabetes support group, which is run by a volunteer community member who has diabetes, and meets every month at a community centre located in the Mirrabooka Regional Centre.

Participants' limited awareness about services and resources was brought to the fore by their direct requests for information made to me during the interviews. As a result,

I provided the contact number of the diabetes support group coordinator to Peter, Alison, Martin, and Bridget and Cecil; and I gave Diabetes WA brochures to Peter, Tony and Lee.

### ***Cost as a barrier to accessing healthcare services***

Participants' accounts revealed that cost was a barrier to accessing healthcare services, and their narratives around this issue highlighted their perception of their own disadvantage on the grounds of their low incomes.

Although the background questionnaire used to collect socio-demographic and diabetes-related data from participants did not include any question on private health insurance, participants commonly disclosed their private health insurance status in the context of discussing the medical care of their diabetes and other medical conditions. Most participants reported not having private health insurance, and relied on healthcare services available through the Government-funded public health system. Only four interview participants spoke of having private health insurance, or 13 per cent of the total sample of 30 interview participants – compared with 44.5 per cent across the Australian population as of June 2008 (PHIAC 2008).

Regardless of their private health insurance status, all participants reported accessing GPs who bulk-billed for their services, which meant that they did not incur any out-of-pocket expenses. Tony revealed that the reason why he had decided to change his GP two years earlier had been that his doctor did not bulk-bill; he comments on his experience of the hassle involved in getting partially reimbursed by Medicare:

*He didn't bulk-bill, so I had to pay the money, and then I had to find time to go over to Morley [neighbouring suburb], to the Galleria [suburban shopping centre] and uh... what a hassle! And being by myself, shopping, doing your washing, getting things ready for work... so much of a hassle, you know. And [my new doctor] bulk-billed, and, you know, I didn't mind paying the money, it's just the inconvenience of me going over to Morley. There's not enough Medicare offices here, you know.*

[Tony; 50s; tablets; diagnosed 10 years]

Participants commonly reported cost as a barrier to accessing healthcare services other than their GPs, and highlighted the difficulty in facing upfront payments, and the resulting out-of-pocket expenses derived from Medicare's limited reimbursement. Cost was cited by several participants as a barrier to accessing

podiatry services. Patricia talks about why she does not visit a podiatrist, and her account reflects participants' shared experience of the need to balance priorities in the context of their limited incomes:

*I keep getting told I should, and I don't. I think, I'll go next week, but next week never comes because there's always something else. My sister usually does my toenails for me, but she keeps saying 'you know, you have to go'. [...] I know it is [important]. But it also worries me. It's fifty dollars and, I mean, fifty dollars is a lot of money. I know my health is very important too, but when you're struggling to pay the bills...*

[Patricia; in her sixties; on insulin; diagnosed for six years]

Similarly, Mandy, who is unemployed and lives by herself, reported that the cost involved in accessing her ophthalmologist stopped her from scheduling another appointment. During the interview, Mandy came across as being shy and not very articulate; however, her detailed recollection of her last visit to the ophthalmologist suggests how deeply she was affected by this episode:

*I'm supposed to make an appointment to go and see the ophthalmologist, but I didn't make another appointment because I first went last year, and they wanted eighty-four dollars for the day I went there, and because I didn't have it, and I said 'oh, can I take the bill with me?' And [the receptionist] got a bit stroppy with me. [...] And she didn't wanna do it, but she gave me the bill and the Medicare form and she said, 'you know, next time you've got to have the cash'. And I thought, 'yeah, well it's all right for you to say'. And I was due to go back, when was it? January or February [...] But this time they want a hundred dollars. [...] And when you're on a limited income, a hundred dollars is a lot of money. Yeah, 'cause usually my money is all accounted for before it comes out the bank; 'cause my rent comes out before I get it, and I pay... I've been paying tax on my payment, ever since I sort of started on it, that's another twenty dollars gone, and I've got an advanced payment in February, to pay the registration on the car, because I didn't have that money upfront either, and they take that back forty dollars a fortnight. So that's a hundred and... a hundred and sixty dollars, you know, gone before I get it, so, yeah...it's pretty tight. [...] I mean, it's alright for her to say, you know, 'oh, you'll get forty dollars back from Medicare', but – forty dollars I think she said – but that's... that's bugger-all to me, you know, don't cover very much forty dollars, you know. And it still leaves me sixty dollars out-of-pocket.*

[Mandy; 50s; tablets; diagnosed two years]

Mandy's account is revealing on several levels: it sheds light on the reality of living on a limited income, where almost every dollar is accounted for, an experience which was common among participants; it highlights the difficulties of facing out-of-pocket

expenses; and it reveals her perception of being judged on the basis of what she cannot afford to pay.

Other participants reported similar experiences. Tony talked about not having seen his heart specialist for the last two years to follow up on his open-heart surgery; he reflects on his impressions of his heart specialist's private practice:

*They seem so puffy-nosed, you know, like, you know, 'You're just a working class. We look after people that are on private health insurance; you're not on one' ... And you had the feeling that they... you're just going there, and they want you out that door as quickly as you can because he's got other people that are on private, you know? [...] That's the feeling I've got. I do. And that again... the care is not there. They only want to care for people who... who are on... who can afford a private health care cover, you know. That's stands out like anything, you know, and you feel... yeah...*

[Tony; 50s; tablets; diagnosed 10 years]

Tony's account reveals his perception that he is being discriminated against on the basis of his income, and it also highlights his understanding of class. Alison's account of an incident that took place during her first visit to a podiatrist – which she accessed through a GPMP – conveys a sense of internalised shame induced by society's negative perception of people who live on low incomes. She recalls:

*You know, when I visited a podiatrist, the first, the first session, he said to me, 'next time you come, bring eight or ten pairs of your shoes with you, and we'll see what shoes you're wearing', and I said, 'you know, I don't own eight pairs of shoes', and he said 'oh, really?' like it was a surprise. [...] But you know, we've been pensioners for... you know, I had an accident and ruined my back twenty years ago, and my husband has chronic fatigue syndrome; we've been pensioners for, like, seventeen years, uh... we don't have outside support, we don't have savings, you know, we live, literally, from pay cheque to pay cheque. We uh... we don't smoke, we don't drink, we don't buy take-away food, we're responsible, we don't go to charities, we manage, we live within our means, if we can't afford it, we don't have it, you know, so... we try to be as socially responsible as we can uh... so things like that, like several... on several levels, that was actually really quite embarrassing, you know, it's embarrassing even telling someone about it, you know, that uh... our society uh... values people that are financially successful, and if you're not financially successful, you're judged very poorly, no matter what the circumstances are, you know. It ... uh... for instance, with myself, it wasn't my fault [emphasis] that I had a severe accident, and ended up being incapable of working.*

[Alison; 50s; tablets; diagnosed nine years]

Alison's reflective, articulate account reveals her perception of her own disadvantage. She feels compelled to explain herself and her circumstances, as she perceives that she and her husband are judged poorly on the basis of having been on pensions for a number of years.

## **Perceptions of the quality of care received**

In this section, I present the results on participants' views on the quality of their diabetes care, exploring the impact of these views on self-management. As a result of the central role played by GPs in the medical management of T2D, and given that GPs were the sole provider of medical care for the majority of participants, the main body of the results presented in this section relate to participants' views on their GPs. Participants' perceptions of the quality of care received from diabetes specialists and AHPs, and of the quality of self-management information and resources, are presented separately.

### ***Views on general practitioners***

Participants' views on the quality of their overall care appeared to be shaped around their perceptions of the quality of care received from their GP. Thus, participants who reported having a positive view on their GPs tended to be satisfied with their overall care, whereas those who reported having ambivalent or negative views on their GPs tended to be dissatisfied with their overall care.

Participants' views on GPs varied; however, these views tended to be polarised. Participants who thought highly of their GPs often used emotive language to describe them – 'wonderful', 'very good', 'marvellous', 'amazing' or 'absolutely brilliant' – and their non-verbal cues – softening the tone of their voice, or changing their facial expression, in some cases to an open smile – were consistent with their language. Negative views on GPs also elicited emotive reactions from some participants, with the use of strong language such as 'my doctor is a royal pain in the rear' or 'the doctors... they don't know what they're talking about', suggesting feelings of frustration and despondency.



## What makes a 'good doctor'?

A constant theme throughout participants' narratives was the notion of the 'good doctor', a representation that some participants used to describe their own GPs and others used to describe the characteristics they perceived their GPs as lacking. A picture of the 'good doctor' emerged from participants' narratives as somebody who is understanding and a good listener, and who takes the time to get to know the patient. Having treated family members and being on top of all their medical conditions were also cited by participants as being important. As she explains why she is happy with her GP, Liz encapsulates the views of those who reported being satisfied with their doctors:

*Because he knows our history, he treated my mother-in-law when she had diabetes. We've probably been going to him for twenty-odd years or maybe longer. Because he is also a doctor that you can talk to. You know some are...in and out sort of thing.*

[Liz; 60s; tablets; diagnosed four years]

Liz's husband Bill echoed his wife's account. He recalls how accessible his doctor was when he was caring for his mother:

*He said 'any hassles with her, I don't care what time of the day or night, you ring me straight away'. Straight up, no hassles. And he was good with her, absolutely brilliant. He's an amazing doctor, really.*

[Bill; 60s; tablets; diagnosed 10 years]

Good communication skills, such as taking the time to explain things and listening, were also valued by participants. Rose, a participant who was born in Burma, referred to these skills as characteristics she valued in her GP. When asked if she feels comfortable talking to her doctor, Rose draws an interesting comparison between doctors who 'drop the pen' and those who 'just work with the pen':

*Oh, yes, she's very good at that. Sometimes I'm half an hour in her room, and she listens. She's not the doctor, you know, when you... and she keeps on writing. No. She'll drop her pen, she'll sit down, relax and we'll be talking. Yeah. [...] That's what I like. I don't like doctors who just work with the pen.*

[Rose; 60s; insulin; diagnosed 20 years]

Rhonda, who was interviewed with her husband Jim, and whose account revealed her limited literacy skills, praised her GP's ability to explain things. She refers to her GP as a teacher, as she elaborates on what she values in him:

Rhonda: *Uh... he's not only a doctor, but he's a teacher too, because he teaches you things... I don't know if he's Hindu or what he is, but he's really... and he's really, really cheerful.*

Interviewer: *it's good to have a smiley face when you're going to see the doctor.*

Rhonda: *yeah [chuckles]. But he's good, he's a good doctor. But uh... he sort of teaches you things.*

[Rhonda; 60s; tablets; diagnosed three years]

According to participants' narratives, a 'good doctor' was also somebody that one could feel comfortable seeking advice from, even on personal and family issues. Participants expressed their appreciation of how their GP had provided advice and support for other medical conditions and also personal issues such as depression or the loss of a loved one. Lorraine, whose son is diabetic and whose daughter has a history of drug abuse, explains:

*Even when I get a bit depressed I can talk to him, especially where my son's concerned, and of course, when my daughter was on... on the drugs. She's not on the drugs anymore, but she was taking speed and uh... she was... she became quite abusive, and she was telling me to go home and die.*

[Lorraine, 70s; tablets; diagnosed three years]

Similarly, Patricia, who described her GP as 'wonderful' and whose face would light up every time she talked about him, valued the support she had received from her doctor when her husband died. Sheryl, who reported having seen the same GP for about three years, also commented positively on advice she had received from her doctor which went beyond the management of her medical conditions:

*You can ask him anything, you know, and he'll explain everything right out. And not only that, I had a friend who was dying with cancer, you know, and she'd get things and her doctor never explained things, so I'd get out there and write it all down, and come here and ask him, and then I'd take it back to her, yeah, so, he's very good. And he seems to have time for ya, you know, you go in and talk to him and that sort of thing, yeah.*

[Sheryl; 60s; diet; diagnosed one year]

In participants' narratives, the characteristics of the 'good doctor' were a combination of character traits and communication skills, crystallised by the notion of 'caring'. Some participants expressed their views on their GPs in words that revealed feelings of affection. Martin, a participant who was born in India and whose

account suggested that spirituality played an important part in his life, described his former GP as a fatherly figure of similar Asian background, who never looked at his watch, and who gave him advice on his diabetes and also on his depression. Martin further described him as somebody that one could talk to about anything and who would take time with everyone. Martin sums up his feelings about his former GP as he reflects:

*He loved you, you knew that.*

[Martin; 60s; tablets; diagnosed 10 years]

Similarly, Derbarl Yerrigan clients, who were generally very satisfied with the quality of their care, all mentioned one doctor who embodied their idea of the ‘good doctor’, and described her as ‘someone who cares’. A short exchange between two participants during the focus group encapsulates their opinion on her:

Frances: *Dr [Dr’s surname], she’s really understanding.*

Nicole: *well, the main thing is, she cares about Aboriginal people.*

[Frances; 70s; tablets; diagnosed 40 years. Nicole; 50s; tablets; diagnosed 10 years]

A common theme to participants’ narratives was the impact of their relationship with their doctor on their experience of disease and their reported ability to cope with the demands of self-management. Thus, participants who reported having a good opinion of their GPs reported feeling motivated and being more likely to act on the advice given to them. The analysis of the accounts of Derbarl Yerrigan clients revealed that they held their GP in high esteem, and their narratives reflected the impact on this positive relationship on their attitudes towards self-management. When discussing medical care during the focus group, Nicole comments positively on her doctor, and provides an insight into her experience of other GPs:

*I feel like I want to do what she asks me to do... with some doctors I don’t want to do it because the way they come across at you.*

[Nicole; 50s; tablets; diagnosed 10 years]

Renee echoes Nicole’s comment, adding:

*Gives you more courage to do things about your sickness and things.*

[Renee; 50s; dialysis; diagnosed 20 years]

In addition, participants who reported having a good communication with their doctors generally reported feeling comfortable asking questions, and feeling that they could contact them if they needed to. This perception that their doctor was accessible made them feel more empowered and better equipped for the demands of self-management, even if it never materialised in actual questions or contacts. Liz's comment articulates this view:

*He knows us and you can actually talk to him, you know, where, I mean, some doctors I have been to, they dismiss you. [...] Because you know, sometimes people ask questions that might seem stupid to the doctor, but it makes sense to the person themselves.*

[Liz; 60s; tablets; diagnosed four years]

This ease of communication resulting in a sense of increased self-efficacy was not shared by all participants. On the contrary, a number of participants spoke of feeling that they were being talked at or given instructions by their doctors, which gave rise to feelings of frustration. Participants who reported issues with weight control commonly spoke of feeling that they were blamed for their disease; this was an issue which was articulated frequently during the non-Indigenous focus group. Diane, a mother of two in her twenties, expressed her frustration at being repeatedly told by doctors to lose weight with a vivid remark:

*I know my weight is an issue. I've got mirrors in my house!*

[Diane; 20s; tablets; diagnosed one year]

Although Diane's comment was met with general merriment by the rest of participants, her feeling of frustration was shared by all. Anne, who is on insulin and has several co-morbidities, reflects on this issue and draws a powerful comparison between her situation and that of an alcoholic:

*It is very annoying when you go to your doctor and they say 'here's the diet sheet, off you go'... If you went there and said 'I'm an alcoholic, I need help', he wouldn't tell to go off and stop drinking, they'd be referring you on. And it is annoying when you are trying your best to lose weight and you can't, and you just get this...*

[Anne; 50s; insulin; diagnosed 10 years]

Christine provides a similar account, as she comments on how she perceives doctors' advice on self-management, and how she gave up asking for advice and looked for an alternative source of information:

*Well, basically they don't completely comprehend. They do give instructions, 'put your feet up, do this, don't do that', but life...you've got responsibilities, you've got to do things [...]. I gave up and I went to a diabetic group one evening at Osborne Park. And I just sat there and I listened to everybody else. And I just sat there quietly listening, and I think I picked up more information that was helpful there than I was ever given before by any of the doctors.*

[Christine; 60s; tablets; diagnosed 20 years]

Christine's course of action highlights her resourcefulness, as she was able to seek alternative sources of support and advice on self-management that were effective for her. On the contrary, participants who did not display strong self-efficacy and who reported not getting enough support from their doctors shared a sense of powerlessness, and reported feeling lost and left to their own devices.

Participants showed little understanding of the technical aspects of the quality of care received, that is, whether their GPs were performing the appropriate examinations and investigations, and making the appropriate referrals. This limited their ability to construct their views on the quality of their care around the technical aspects of their medical management. Peter provides a typical description of the blood tests he has done regularly:

*I think it's just the glucose level. I don't know much, I just go there, put my arm and...*

[Peter; 50s; tablets; diagnosed seven years]

Similarly, Sheryl, who reported being satisfied with her GP, talks about the tests she has done when she sees her doctor:

*Everything. I forget...oh, whatever they do in the blood test. He's very good; explains the whole lot [...] From the cholesterol to kidneys, liver, whatever... the whole lot, yeah. I don't understand half of it, but he says if it's this or if it's that, over that or over that, yeah, so... but he sees the whole lot.*

[Sheryl; 60s; diet; diagnosed one year]

Although in her comment Sheryl acknowledges that she does not understand 'half of it', in contrast with Peter, she experiences the medical encounters in a positive way, because she perceives that her doctor explains everything, performs all the necessary tests and takes action accordingly.

Lorraine, a participant who reported being satisfied with her medical care, provided a detailed account which set her apart from the rest of participants. Lorraine explains the thorough examination she undergoes every time she sees her GP, and her narrative reveals a good level of communication with her doctor, and her sound understanding of the different components of the medical management of her disease, which is consistent with her previous detailed account of her regular visits to the podiatrist:

*Well, every time I go, he makes sure... I take that with me [the BSL booklet] and he checks, then he checks himself sometimes, and he monitors my blood pressure and all that. He said he could tell by the pulse and everything whether everything's... and he checks my feet and everything. And I turn around and say, 'why do you have to do that?' He said 'when you've got sugar diabetes [...] I just got to make sure that you're not going to get any sores that are not going to heal'. And he turned around and said, 'I've got to watch everything. If you knock yourself you come straight to me, especially if you've broken the skin because it is hard to heal up, because of your sugar'.*

[Lorraine; 70s; tablets; diagnosed three years]

Appropriate referrals are another technical aspect of good diabetes care which was mentioned by few participants. Some participants, although not believing that they needed a referral, thought positively of their GPs because they perceived that they would not hesitate to refer them to a specialist or allied health professional if needed. Bill's comment about his doctor sums up this view:

*If he's not sure of something, he'll recommend us to a specialist, he won't muck around.*

[Bill; 60s; tablets; diagnosed 10 years]

Two participants, Tony and Peter, reported having requested their respective GPs to refer them to a dietician several times without success, and in both cases this failure to act upon their request negatively influenced their views on their GP, and gave rise to feelings of despondency. Peter talks about his unsuccessful attempts at obtaining dietary advice:

*Oh, I've just given up. I've given up asking to try and get it. I've given up asking for referrals to where I can get it. Like I said, my GP is not very helpful. He seems to think that I can manage my own diet plans, and unless you know what you should eat and what you shouldn't eat. So I still eat potato... bad! [...] I've told him to his face. I said 'what's the point of asking you for any help if you're just not helping me?' And he*

*said, 'well, you know that's the way it is, you can manage your own diet', but unless I know what I should be eating and what I shouldn't be eating, I don't know!*

[Peter; 50s; tablets; diagnosed seven years]

Finally, Alison reported experiencing poor glycaemic control for eighteen months before her GP referred her to a diabetes specialist. Having been exposed to a multi-disciplinary team through her participation in a drug trial, Alison reflects on her experience in hindsight:

*Looking back at it, I don't feel that my doctor was supporting me very much at all, actually. Uh... it was only after I had the three consecutive slightly higher readings that he actually did something about it.*

[Alison; 50s; tablets; diagnosed nine years]

### **'It's your sickness': The role of doctors in the management of diabetes**

Participants' views on the quality of their care were also shaped by their perceptions of their own agency, and of the role played by their doctors in the management of their disease. This role was, in turn, influenced by what many participants perceived as being rushed consultations that left no time for meaningful communication between patient and doctor.

A common theme to participants' accounts of their self-management was that of 'ownership' of their disease, which entailed an attitude of personal responsibility for their disease management. References to diabetes being 'your disease' or 'your sickness' were frequent in participants' narratives, and many emphasised that it was 'your responsibility' to do something about it. Dot, an Aboriginal woman who reported being involved in health advocacy work and whose account revealed a high level of self-efficacy, reflects:

*I think it's up to yourself whether you change and make your life better for yourself. Like I said, uh... if you don't want to change, well, nobody else can make you change; it's up to you, the person, if you want to change.*

[Dot; 70s; insulin; diagnosed 35 years]

Dot's comments above highlights her views on the importance of the role of the individual as an agent for change, and is consistent with the rest of her narrative, which revealed her strong sense of her own agency in making a good life for herself and her son, whom she reported having raised single-handedly.

Renee, who took part in the Indigenous focus group, sums up this view:

*It's your sickness, hey, because nobody else is going to do it for you.*

[Renee; 50s; dialysis; diagnosed 20 years]

As part of this process of taking responsibility for their own disease, participants emphasised the importance of the 'care of self'. References to the importance of 'looking after yourself' and 'taking care of yourself' were common among participants, regardless of their reported glucose control and health status. Rose recalls the conversation she recently had with a friend, also diabetic:

*And I've got a friend who's... who is a diabetic, who's a naughty girl; she smokes, and she... oh, she does everything. And the other day she had two heart attacks, so... I said to her, I rang her up and I said 'come on, love', I said. She said, 'no, I have nothing to live for'. 'No, it's not that', I said, you know... 'you have to look after yourself. Diabetes, you're not going to have somebody to look after you, because it's your body', I said, 'you have to take care of it'.*

[Rose; 60s; insulin; diagnosed 20 years]

Mary reflects on what she thinks is making a difference in keeping her BSLs under control, and her remark encapsulates participants' views:

*I think it's looking after yourself, that's what counts.*

[Mary; 60s; insulin; diagnosed 15 years]

In some participants' accounts, the notion of being responsible for your own disease was accompanied by an ambivalent attitude towards the role of doctors in the management of diabetes. The following exchange between two participants who took part in the non-Indigenous focus group illustrates this point. Christine and Anne both reported having experienced diabetes complications; they were of a similar age, and they seemed to develop a rapport during the session, often engaging in exchanges. After discussing her views on the importance of a good quality of life, Christine makes a disparaging comment about doctors, which prompts Anne to reveal her own view that doctors 'can only do so much':

*Christine: the doctors... they don't know what they're talking about. I know for a fact that I've got diabetes, and I know for a fact that I'm the one who's responsible.*

*Anne: yeah, they can only do so much.*

[Christine; 60s; tablets; diagnosed 20 years. Anne; 50s; insulin; diagnosed 10 years]



While a few participants perceived the role of their doctor as confined to that of a disease management overseer and medication prescriber, and accepted this, many appeared somewhat confused by what they perceived as their GP's lack of interest in their condition. Marko, a participant who reported being on multiple medications for several conditions, reflects on the quality of his medical management and his comment reveals his belief that doctors should do more than just give medications:

*It's pretty good, but they don't do... they can't do much if they just give you the medication, like you always take it. They're repeat prescriptions. Medications... really they don't do that much for you, they don't make you... they don't make you any worse... but they don't cure, you know.*

[Marko; 70s; tablets; diagnosed 10 years]

Similarly, Peter, whose account was dominated by his frustration at the lack of support he reported receiving from his GP, reflects on the limited role of doctors generally, revealing his ambivalent views:

*Most doctors will just give you pills and send you home, hoping that will make you right, but it really doesn't.*

[Peter; 50s; tablets; diagnosed seven years]

A common perception among participants was that doctors spent more time filling in paperwork during their consultations than talking to them, which elicited feelings of frustration and scepticism among participants. Paul, a participant in his early eighties who during the interview admitted to being 'very sceptical' about doctors, comments:

*Well, I'm interested in my well-being, and the doctors are a bit casual about it [...]. To me it looks like he couldn't care less.*

Later in the interview, he adds:

*He's a nice sort of a chap, he's a nice chap, but, uh... but he knows, when he gets his forms back from the... from the laboratory, he puts a tick on... you know all those little boxes... and it's all 'file', so I come and get a copy and file it.*

[Paul; 80s; diet; diagnosed 18 months]

Some participants perceived that there had been a shift from the doctor playing a proactive role in medical management to the patient playing the central role during the course of the consultation; they reported having to request everything from their doctors and drew comparisons with the 'old days' when doctors were family friends

who knew them and who conducted thorough examinations. Marko reflects on what he perceives all GPs to be like today and his remarks – laughing off as he describes his experience – reveal his scepticism about the healthcare system:

*The GP is... a GP. You know how they are GPs today [laughs]. They got too many people there, they don't talk to you much, they just say 'what you wanted today', you explain what's wrong with you, and they check your blood pressure sometimes... But, you know, it's not a thorough examination like it used to be; doctors, you know, today is more like... more sort of... like everything else today, in a hurry. Two, three minutes and you're out of the surgery [laughs]. And then if something's wrong with you, you go back [laughs off].*

[Marko; 70s; tablets; diagnosed 10 years]

A similar experience was reported by Jim. He reflects on the care he and his wife Rhonda have received over the years, and provides the analogy of the general practice as a 'battery-hen farm':

*Generally, you can appreciate, generally a lot of times, it's just a quick... like a battery-hen syndrome, in and out quickly, and that's where a lot of the concern is.*

[Jim; 60s; tablets; diagnosed eight years]

This view is echoed by Tony, who, similarly to Jim, reported having changed his GP due to a bad experience. As he compares his experience of a consultation to a 'drive-away service in a garage', Tony encapsulates participants' perception of the medical encounter:

*When I was younger, you know, [...] you'd go and see your GP. The GP, the first thing he'd say is 'hey, how are you feeling?' A little bit of a conversation, and then up your sleeve and they would check your blood pressure, they would... you know, check your diabetes, uh... But these days, they don't do that, you have to request. And sometimes, you know they're very busy, and they don't do that, you know, the doctors today, they don't... you know, all that's gone. It's like a drive-away service in a garage: they come, 'oh, would you like your window washed, uh... tyres checked up?' You know, doctors are just... you know, getting 'what do you want your script?' They knock it up on a computer. That's it. See you later.*

[Tony, 50s; tablets; diagnosed 10 years]

## **Perceptions of other healthcare professionals**

Participants' views on the quality of care received by healthcare professionals other than GPs, including medical specialists and allied health professionals, are described here. Participants were less able to articulate their views on the quality of care received from other healthcare professionals as their experiences of access were, generally, more limited. Participants reported lesser access to health professionals other than their GPs, and when access did materialise, participants reported significantly less frequency of access (typically, a yearly visit or a one-off session).

### **Views on diabetes specialists**

Participants who reported seeing a diabetes specialist were generally satisfied with the quality of care received. Their accounts suggested that participants had an internalised hierarchical value system, where specialists sat at the top of the medical pyramid, and had their patients' implicit trust. Patricia's comment reflects this view:

*He's really a professor; he's not just a doctor. He's a professor, so I mean you'd know that he knew what he was talking about.*

[Patricia; 60s; insulin; diagnosed six years]

Participants' views on the quality of care received from their specialists highlighted issues that were more a reflection of the healthcare system as a whole than of specialists themselves. Thus, for example, some participants commented negatively on long waiting times to see their doctor. Marko, who reported having accessed an outpatient Diabetes Clinic when he first moved to Perth, recalls his negative experience at the clinic and what happened when he complained to a staff member:

*'Cause I said that I'm not going to wait three, four hours every time I go there [laughs off] with all those people... They don't have any room; they sit there in the passage, you know, everybody walks past and pushes you around. I said I wasn't very happy, she said 'well, you don't need to come here', she said 'we don't want you anymore'. I got to pay for the parking... all those people there, you know, with diabetes, and only an old woman, volunteer probably... [laughs]. It's all dirty there, everybody passing... walks past there and pushes you around...*

Later in the interview, Marko adds:

*The diabetic clinic in [tertiary hospital] is... they're very rude there, they do nothing for you, just stick the needle in and uh... and send you on your way, and that's what you got to wait three or four hours there.[...]*

*They don't tell you nothing about the diabetes or anything. It's just wasting of time to go there really; wasting of the Government money, too, to be there. That's what I would tell them...*

[Marko; 70s; tablets; diagnosed 10 years]

Similarly, Michael, who is on insulin and reported seeing his specialist once a year, gives his impression of the diabetic clinic he accesses, leading him to conclude that 'the system is really bad':

*You know, they haven't got much work... They say they're busy, busy, but those nurses, as you come, they're walking around, they just say, 'alright, Michael, come, let's check your blood sugar'. And that's about all these nurses do, you know? They don't do anything much, anyway. What I've seen, 'cause I go there, I'll be sitting down for hours, actually. My appointment is at two o'clock, I don't get seen until four o'clock. And you see these nurses sitting down, the door is there, you're sitting down, and you can see them sitting down there and just walking around... that's about it. So the system is really bad; that system is bad, I reckon.*

[Michael; 60s; insulin; diagnosed 15 years]

Another issue raised by participants was the lack of continuity of care at the diabetic clinics. Dot, a Derbarl Yerrigan client, provided a unique account, reporting that she had seen the same specialist for the last 30 years. Other participants who reported seeing a specialist, however, had a different experience, as most reported seeing a different doctor at every visit. Rose talks about her experience:

*I was supposed to have him to control... you know, to keep me under his wing and look after my diabetes. But it's only him on the card; I've never, ever seen him, right? I don't know... When I go, I say, 'Am I seeing Dr [Dr's surname]?' 'Yeah, yeah, yeah'. And suddenly there's another doctor. I say 'is this Dr [Dr's surname]?' 'No.' 'Why can't I see Dr [Dr's surname]?' 'Oh, he's very busy, madam'. 'OK, fine.' So it went on for years and years, and then I got fed up. I said I don't care whoever sees me, you know. So, as long as I [emphasis] am the one controlling my diabetes; it's my body, it's up to me to control it, right?*

[Rose; 60s; insulin; diagnosed 20 years]

Rose's final remarks are revealing, as she appears to have resigned herself to the fact that she will be seeing a different doctor every time, and her account suggests that she is trying to persuade herself that this is fine by bringing forward her beliefs around the importance of her own agency.

Patricia's experience of accessing specialist services at a diabetic clinic is included in detail, as it highlights her experience of the reported inflexibility of the outpatient

system currently in place, and its impact on the patient's experience of health care. Firstly, Patricia describes why she sees a different doctor every time she has a specialist appointment:

*Patricia: I go into the diabetic clinic at [tertiary hospital]. I used to see Dr [Dr's surname]. And then I missed a couple of appointments because when [my husband] died, I may not... I had an appointment, and we had to hold the funeral up for a month because his family had to come out from England, and my next appointment was then, so, of course, they got stroppy with me, and now every time I go in there I see someone different.*

*Interviewer: they got stroppy with you because you missed the appointments?*

*Patricia: because one of the appointments I didn't notify them. Well, I mean, when he passed away, I was distraught, of course, and I didn't think about the diabetes appointment that I needed to cancel, so, of course, I didn't do it, so... they just wrote back and said you've been taken off [the doctor's list].*

Later, she explains the rules that apply to outpatient appointments:

*If you miss two appointments to any hospital without notifying them, they cut you off. Then you have to go back to your own GP, and you've got to get another referral.*

Patricia describes a negative experience which brings to the fore the implications of the lack of continuity of care for a person with a complex medication regimen:

*So now I only see the registrars. And I've had a couple of run-ins with the registrars. Some have been very nice, but uh... one of them went in there and he said to me 'what medication are you on?', so I told him, and he said 'oh, you can't have that, that's no good for you. I'll change you'. I said 'no, you won't'. I said 'I've been on this since I was told I was diabetic, so I don't intend changing'. If it had been someone like my own doctor or one of the head doctors... because he then had to go out and get permission to do this or ask a question, and he was going to change my medication? As the saying goes, if it's not broken, don't try and fix it. So I got real upset with him. Then he said 'we'll do it, because that's what I'm here for'. And I said 'no, you're here to help me, not to... do it', so he said 'oh, I want you back in here in a month's time to check you', and I thought I've been diabetic all these years, I haven't had any problems... why? So when I went back in, of course, he wasn't there, he'd been moved on.*

Asked how she feels about seeing different doctors all the time, Patricia's immediate reaction reveals how strongly she feels about this issue:

*Oh... it really... it really makes me mad at times, because you don't know where you're going to go, what happened, so... I like the idea of seeing the same person, seeing my own doctor.*

[Patricia; 60s; insulin; diagnosed six years]

### **Views on allied health professionals**

Despite the limited evidence of access to allied health professionals (AHPs), several participants reported bad experiences, particularly with dieticians, but also with podiatrists and physiotherapists. The narratives of some participants around AHPs revealed feelings of lack of trust and scepticism. Paul recalls an encounter with a podiatrist, whom he perceived as only being interested in selling him orthopaedic inserts for his shoes:

*He just gave me the cold shoulder after he saw that I got them. I said 'I got them'. Showed him my shoes. He lost interest in me then.*

[Paul; 80s; diet; diagnosed 18 months]

Michael and Rose both had negative views on AHPs, and both reported having had bad experiences with them. Michael held a sceptical view on the quality of their services and was almost disdainful of them. Prior to his interview, I had been warned by his wife that Michael had had an incident with a physiotherapist recently. As the interview unfolds, I tentatively broach the subject with Michael, who is happy to talk about his experience:

*'You must do this, you must do that' ... never checked me, never touched me... nothing, nothing. Just talking to me like that. I said 'you blokes are' ... I said, 'you blokes are cheating the Government', I said, 'by taking people's money', I said, you know. And, no, I had a big argument with him.*

[Michael; in his sixties; on insulin; diagnosed for 15 years]

### **Perceptions of the quality of self-management education and resources**

Participants' views on the quality of the diabetes self-management education and resources received within the healthcare setting since their diagnosis are discussed here. Participants generally viewed the information received as useful but often overwhelming, and they wished for information tailored to their specific needs.

## Useful but overwhelming information

Overall, participants reported that the information on diabetes self-management they had received had been useful, as it had provided them with information they did not have, and practical pieces of advice which they were able to implement, for example, replacing potato with sweet potato, cutting the fat off meat when cooking, or identifying fruits with the lowest sugar content.

A common theme to participants' accounts was the initial overwhelming feeling of having to absorb a lot of information, especially at a time when they were still trying to come to terms with their diagnosis. The use of words such as 'scary', 'overwhelming', 'confusing' or 'daunting' was common among participants when describing the information received after their diagnosis, particularly among those who had attended a structured education course, pointing to a possible failure of the healthcare system to provide diabetes education in a safe, nurturing environment promoting self-efficacy.

Nicole, an Aboriginal woman who took part in the Indigenous focus group and whose account revealed very poor glycaemic control and dietary habits, recalls the information she was given, and her account reflects most participants' experience:

*I found it quite difficult, because when I first was diagnosed, you're rushed with all this information, your diet, the care of your feet, how it works and all this. And trying to get your head around it... And then, you know, you're left to manage whatever they say you've got to do or look at... It took ages to try and sort that out.*

[Nicole; 50s; tablets; diagnosed 10 years]

Alison used words such as 'scary', 'frightening' and 'overwhelming' to describe how she and her husband felt when they attended the diabetes education session. She reflects on her impressions on the course and her comment highlights her views on the limitations of one-off education sessions:

*I feel that a one-off class, when you've just had this diagnosis, and you, you know, there's a whole pile of people there, and, although the staff, you know, they were very well intentioned, they seemed to forget that we're lay people, we don't understand some of the terminology, and it's all a bit scary and a bit frightening, and they really give you overload on the one day, and it was just two lectures, and that was it. And then it's like you're on your own. Uh... it was rather overwhelming, both my husband and I, you know... My husband came home and was like, you*

*know, 'wow! How on earth are we meant to remember all of that?' Uh... and really that was it; there was never any other back-up suggested.*

[Alison; 50s; tablets; diagnosed nine years]

In her comment, Alison refers to the lack of follow-up after the one-off session, something that was experienced negatively by other participants, who described feeling as if they were 'left to their own devices'. In contrast, Anne, who took part in the non-Indigenous focus group and reported accessing one-on-one sessions with a diabetes educator at a diabetes clinic, reflects on her experience and acknowledges how fortunate she is in comparison to others:

*I've been lucky with the diabetes educator, for an hour, it's a one-on-one, and you don't feel like you're being shoved off. If you say to her, 'look, I don't understand that', she'll go through it again. And not everybody who's out there goes to a diabetes educator on a one-to-one basis.*

[Anne; 50s; insulin; diagnosed 10 years]

Some participants reported being given pamphlets and other written material, and commented on how this helped them absorb the information and allowed them to refer back to it when needed. Mandy, who reported that both her mother and her late father had diabetes, recalls:

*It seemed a bit daunting at first, but yeah, it's very helpful once you decide, yes, I must sit down and read it; and once you get going, yeah [...] Well, I did know, like, something about diabetes, like... because of my parents, but there was a lot also I didn't know, so the information helped, yeah.*

[Mandy; 50s; tablets; diagnosed two years]

Similarly, Sheryl reflects:

*You can always refer back to them, you know; if there's something that you wanna know, you can always go back to it. If you'd thrown it out you can't. But as I find now, I mean, things sort of go in one ear and out the other, but, uh... you know, the memory is getting a bit... not too bad, but yeah, you do forget things and that. So I can go back and check that out again.*

[Sheryl; 60s; diet; diagnosed one year]

Participants' accounts on the quality of the self-management education and resources revealed that most managed to get some use out of it. However, some appeared to find the experience too overwhelming. Diane, a young single mother who took part



in the focus group, recalls the information she received at the time of her diagnosis of gestational diabetes:

*I got no information on what I had to do, how to manage what I had as such, I mean manage it as such because I was told how to do this, 'this is how you cook, blah, blah, blah' ...but other than that, you kind of look at it and went 'what do I have now?' And it confused the crap out of me. And she [the nurse] had diabetes, and she still confused the crap out of me. I mean... I like blunt terms... because it's so much easier, it's like sit down and cook, point A, point B... She gave me... she gave me this diagram with all these... like a little key sort of thing, and I still didn't understand it. She went through it so quickly and I was kind of like, well, you've got it, too bad, so sad. If you want to get right of it, lose weight, you'll be right... so I won't ask questions now...*

[Diane; 20s; tablets; diagnosed one year]

Diane's colourful language conveys how confusing and overwhelming she found the whole experience. Her account also provides an insight into how a session designed to educate and empower can be experienced as a disempowering event.

### **Need for adequate and tailored information**

A common theme to participants' narratives was the importance of being treated individually. The common view among participants was that everybody is different, diabetes affects people differently, and pieces of advice and information which are relevant to one person are not necessarily relevant to another. Anne, who reported being on insulin and multiple medications, encapsulates this view:

*You can't treat everybody the same, because we're all individuals, and what will work with one is not going to work with another.*

[Anne; 50s; insulin; diagnosed 10 years]

This common view suggests that there is a need to provide information which is tailored to the person's unique set of circumstances, including their physical, cultural and social environment, and to which the person with diabetes can relate. Frances, who attended the Indigenous focus group, talks about how she felt about the advice she was given on exercise:

*Well, if you're a sports person, you probably can relate to it [...]; but then, if you're not, you know, sometimes you need to make sure that you're right, you know, because of your sickness.*

[Frances; 50s; tablets; diagnosed 40 years]

The Indigenous focus group provided the opportunity to discuss the adequacy of pamphlets and other written information on self-management, and the need for this information to be culturally appropriate and written in a language to which people could relate, or as Robert – the only male participant at the focus group – succinctly put it: ‘no big words’.

Another issue which highlighted the need to provide tailored information was that of the unintended consequences of the advice received. Alison, who admitted to having felt overwhelmed by the information provided at the education session, recalls:

*They say to you, you know, base your diet on fruits and vegetables; but then they don't tell you, but you've got to restrict the type of fruit you eat, you know, you're supposed to eat apples and pears, you know, slightly green bananas. You mustn't really eat, you know, watermelon or rockmelon or grapes, because their GI is very high. So the first thing I did was, OK, I'll go out and buy heaps of fruit, and eat lots of fruit, and I'm thinking, oh, I'm doing so well. And then test my blood sugars, and they're thirteen, and I'm thinking, what have I done wrong? Nobody told me that, you know.*

[Alison; 50s; tablets; diagnosed nine years]

Lorraine, who is in her seventies and has a history of iron-deficiency anaemia, told a similar story, recalling how she lived on salads only for a month after her diagnosis, until her GP found out and advised her to incorporate meat to her diet. Patricia revealed another unintended consequence of the way in which information on self-management is delivered; she recalls the main focus of the education session:

*And then, you know, what they kept pushing at me is you must have food within fifteen minutes of having your insulin. And I became quite paranoid about it; so I got to the stage where, unless food was sitting in front on me, I wouldn't have the insulin.*

[Patricia; 60s; insulin; diagnosed six years]

Finally, another aspect of the education session which was experienced negatively was the perceived emphasis on what foods should be avoided rather than on those that could be incorporated into their diet, as Alison points out:

*The dietician did a very long session, and you know she had lots of packets of food, and she was talking about the glycaemic index, which wasn't quite so well known about then, uh... which was also quite confusing, you know. It was a lot of emphasis played on what you can't eat, you know, 'you mustn't have this and you mustn't have that', but I*

*felt at the time, not enough emphasis was placed on what you should be eating, you know.*

[Alison; 50s; tablets; diagnosed nine years]

## **Conclusion**

Participants' reports of the medical management of their disease suggested an inconsistent model of care. Derbarl Yerrigan clients, however, reported a model which more closely followed that recommended for people with T2D.

Regular access to GPs was reported by most, but not all participants. Regular access to ophthalmologist and opticians was widely reported, while evidence of access to AHPs was very limited. Cost was reported as a barrier to access to any healthcare services that involved out-of-pocket expenses. Perceived need for services, lack of information on available services, and previous negative experiences of episodes of care also influenced healthcare-seeking behaviour.

Participants valued personal traits and communication skills in their GPs, rather than their technical competence. Their views were influenced by their attitudes towards the role of doctors in the management of their disease, and medical encounters were generally experienced as being rushed and leaving no time for meaningful communication between doctor and patient. Negative experiences of allied health were reported by several participants.

Information and resources on self-management were perceived as useful but overwhelming, and participants wished for adequate information tailored to their specific needs.



## Chapter 10 – Priorities for the Effective Management of Type 2 Diabetes

In this chapter, I present the findings around participants' views on the priorities for the effective management of diabetes. The results presented in this chapter relate to the study's third and final objective:

To elicit the priorities for the effective management of T2D from the perspective of disadvantaged health consumers.

The findings discussed in this chapter relate to participants' opinions on what the priorities for a more effective management of diabetes should be, and more specifically, how diabetes healthcare and support services could improve in order to support people living with diabetes in the community better. Although the priorities elicited reflect participants' own personal experiences and values, the findings presented in this chapter relate to participants' views on systemic improvements to the existing resources and services available rather than their views on how their specific circumstances could improve.

The data gathered to address this study objective were more limited in scope and richness than those relating to the first two objectives. This was due to the following reasons: this aspect of the study could only be partially explored with Derbarl Yerrigan clients due to the time constraints and circumstances surrounding the interview process (see Chapter 4); in addition, it proved difficult for some participants to elaborate on their responses as this process required a higher level of health literacy and insight which not all participants shared; finally, participants who reported being on diet-only management and those whose accounts suggested sustained glycaemic control tended to have less exposure to health services, and some felt that they were not in a position to give their views on any improvements to existing services. As she reflects on her and her husband's experiences of health care, Liz provides an account which illustrates this view:

*For Bill and me, I think it's fine. And I think unless you're in that position, you really can't say.*

[Liz; 60s; tablets; diagnosed four years]

## Community-based resources

Having easy-to-access community-based services was identified as one of the main priorities. Participants highlighted the need for more information on existing services and resources to be made available locally; they also pointed out the need for services and resources to be more easily accessible; and they identified specific support and healthcare services which they perceived as most needed.

### **More information on available services**

As discussed elsewhere (see Chapter 9), participants had limited knowledge on available services and resources, and they tended to rely on their GP as a source of information. Many participants perceived that the information on available services was too scarce, and they wished to see this information more widely available and easily accessible in the community. Peter, for example, comments on the lack of information on support groups:

*Well, nobody's told you, so you're flying blind; you don't know where they are. And you go to the doctor's surgery, and you'd think there would be something on the medical board where they've got flyers, support groups and... surely they could do a big list with all these support groups. Because I do believe that's what you need, because people are a good support to each other with the disease.*

[Peter; 50s; tablets; diagnosed seven years]

Peter's comment on the need for flyers and other written material to be made available at doctors' surgeries was echoed by other participants, and local chemists were also suggested as a point of information for people with diabetes. Patricia reflects on the role she believes chemists could play in relation to the provision of information, reasoning that chemists are places which are already being accessed by people living with diabetes:

*[...] the chemists, usually you go in there and say 'I'm not feeling too good' or whatever, or... they can hand you a card, they can talk to you about... So people could even go to their chemists. And then the chemist could say, 'look, I can't help you anymore, maybe if you contact...' and so they help that way as well. So that also makes people feel like there are people out there that care. [...] So it all comes back to the place where you get your stuff from to help you.*

[Patricia; 60s; insulin; diagnosed six years]

In her comments, Patricia also touches on an additional role chemists could play: providing support to those who have no other support mechanism in place, making people feel like there are ‘people out there that care’.

### **Accessible services**

Participants perceived accessibility as an essential characteristic of any support and healthcare service for people living with diabetes. Thus, in participant’s narratives, services needed to be based locally, and they also needed to be directly accessible without the need for a referral from a GP.

Some participants struggled to attend their regular hospital appointments due to transport issues, as many did not have a car and relied on public transport. Lorraine, who reported using a walking frame because of her balance and mobility issues, spoke of having to stop attending the podiatry clinic at a community hospital:

*Originally I used to go to [tertiary hospital]. I had in-grown toe-nails, and they took one off each leg; the second little one on both feet have been taken off. I had them done at [tertiary hospital], and I used to go back for my feet and ask to be cut there, then they turned around and put me into [local community hospital]. And, I was very sick, and with my leg I couldn’t move very much, and getting a bus, then the train, then the bus, was just a little bit too much for me.*

[Lorraine; 70s; tablets; diagnosed three years]

Similarly, Alison, who was not always able to drive because of a back condition, reflects on the need for community-based services:

*I think if there was some sort of community-based nurse practitioners in our area, even if it was once or twice a month, it would be quite wonderful, because uh... sometimes for people on low incomes, even getting to these appointments is difficult, you know, it’s complicated and it’s hard to achieve, you know. [Tertiary hospital] is quite a long way and if you happen to be relying on public transport, it’s like three bus journeys, you know, it’s... if you’re not well, it’s quite a lot of... to take six bus journeys in one day to get there and back, it’s quite a lot. So I do feel that some suburban-based diabetic care would be wonderful.*

[Alison; 50s; tablets; diagnosed eight years]

Alison’s remark on the additional burden of travelling by public transport ‘if you’re not well’ is consistent with Lorraine’s account, and also reflects the experiences of other participants who reported experiencing mobility issues due to co-morbidities or complications of diabetes.

Adding to the burden of making long journeys to their hospital appointments, parking fees and petrol costs were of concern to participants who reported driving a car, as was their declining confidence in their driving skills. For Patricia, who reported feeling unsafe in her neighbourhood, driving was an essential part of her sense of independence. After recalling how in several occasions she had had to drive to two different chemists to get her insulin or the needles she required, Patricia reflects on her concerns about the future:

*Because there's going to come a time when I'm not going to drive... I mean, I've just turned sixty; I'm not a confident driver as far as... I mean, as I said, I've been driving quite a while and I haven't had an accident, but [emphasis] there's going to come a time I won't drive because the roads are going to get worse, more traffic, with all the young kids getting licences, and it's getting so busy on the roads... I can't see me driving for ten more years. So then... where am I going to go? [pauses] Yes, I know I'm in a good place to get buses, because that's why I bought the land here for this house, because I've got such a good bus service; but there's lots of people that aren't in the same position, as far as public transport, so you need to make it easier for them. And just because you're diabetic, it doesn't mean that you're going to be able to buy a house, or rent a house, near public transport, to get you to where you need to go.*

[Patricia; 60s; insulin; diagnosed six years]

Although Patricia refers to others she perceives as being less fortunate, it is clear that she is concerned about how she will cope when she is no longer able to drive.

In participants' accounts, ease of access to services did not only relate to physical accessibility, but also to direct access without the need for a GP referral. Peter reflects on this issue:

*Well, I mean I've been sitting around for months thinking about all these things and I think that's what we do need. We do need it in the communities, where people can go to get the support. You don't want to rely on getting a referral from your doctor and send you to the hospital and wait and wait and wait and wait. Like I said, nine or ten months down the track it's too late.*

[Peter; 50s; tablets; diagnosed seven years]



## **Support groups and services**

Participants identified community-based diabetes support services as a high priority, and they mentioned specific services including: support groups; diabetic forums, classes and seminars; local diabetes clinics; and diabetes nurse practitioners and diabetes educators.

Support groups were the services most frequently cited as a high priority, and they were seen as sources of emotional and practical support. Bridget and Cecil engage in an unprompted exchange towards the end of the interview which highlights their perception of the need for support groups:

*Bridget: something that I would like to see is more education in each of the suburbs, not like... if there's education across the other side of Perth, you've got to go that far, but in each suburb I think there should be more.*

*Cecil: yeah.*

*Bridget: like a support group...*

*Cecil: there is a need for it.*

*Bridget: in each area. So people, if they feel... don't feel good about it, they can go to these sessions and talk about it with others that have gone through it.*

[Bridget; 40s; insulin; diagnosed seven years. Cecil; 50s; insulin; diagnosed five years]

Bridget's final remark touches on the importance of peer support – sharing information with 'others that have gone through it' – which was echoed by other participants. Participants' call for support groups in the community was often accompanied by comments on the increasing prevalence of diabetes in the community, a fact of which all participants appeared to be well aware. Peter's account illustrates his understanding of the diabetes and obesity epidemics as he comments:

*Having like, I guess, a diabetes support group in the community would be a big help. [...] I mean, I'm not the only one with it [diabetes]. I know there's lots of people around with it. It's a pity in Australia, with all these fast-food stores that come and are here, don't help the issue. And it doesn't matter whether you go down to Mirrabooka, there's a lot of obese people walking around, without a doubt. Many of them will have sugar diabetes for sure; they probably don't know they've got it.*

[Peter; 50s; tablets; diagnosed seven years]

The importance of support groups was also raised during the non-Indigenous focus group, and there was a perception that these groups were not getting the support they needed. Christine, the only participant who reported attending a support group comments:

*I reckon that these special groups, they are under threat; closing down because they're not getting support [...] they are not getting support from the Government. That's very harsh.*

[Christine; 60s; tablets; diagnosed 20 years]

The perception that diabetes was not being allocated the resources required was also shared by Derbarl Yerrigan clients, who advised me that a position of diabetes educator had recently been abolished. Dot, an Aboriginal participant who reported having been involved in diabetes advocacy work, comments on this issue:

*I think there is a lot around; it's just that people don't always tap into things that are out there. [...] I mean it's there for everybody if they choose to want to go out and access, but, like I said, they closed a lot down, which I think it's the worst thing they could have done, to be honest, because if people can't go and talk to somebody, or they don't bother...*

[Dot; 70s; insulin; diagnosed 35 years]

Although participants referred to 'support' groups, their accounts revealed that they viewed these services not only as peer groups providing emotional and practical support, but also as places where they could get on-going support from diabetes-trained health professionals. Peter talks about the need for these services:

*So I really believe it should come back in the community, where there should be support groups; you can go along to them, meet with people who may be versed on what the diet should be, what exercise... and get the support that we need. Because I know I'm not the only one here.*

[Peter; 50s; tablets; diagnosed seven years]

In his comments Peter refers to both diet and exercise as aspects of self-management on which support services could provide advice. During his interview, Peter mentioned several times that he was hoping to find other people in similar circumstances to form a walking group, as he reported struggling to find the motivation to exercise by himself. The need for community-based exercise groups was also highlighted by Marko, who referred to this aspect of self-management several times during the interview. As Marko reflected on what he believed the

Government should do, the raised tone of his voice emphasised the strength of his conviction:

*For old people, Government should subsidise to go to exercises, and would cut down on going to the doctor, and would cut down on the medication... we don't need to take that much medication and we don't need to go to the doctor that many times, we would save the money there, and what they would put into subsidising the chronically-ill old people to get access to the exercises once or twice a week, they would... I think they would help a lot.*

When asked whether he saw that as a priority, Marko emphatically answers:

*Yeah, yeah, that's the main priority, exercises, that's what we need. They say you go for a walk, but many people they can't walk, you know... you can walk slow, but slow walking doesn't do that much... When I go to walk the dog... I can't walk with a fast speed, you know, fast speed to get the heart going. And when you get those exercises, and continue to do that once or twice a week, you get... the system start to... build yourself up, and things start to get better, you know. That what... I think that what it is. Still need the medication, but maybe not that much; after a while you start to feel better, stronger and blood get more through your body, and the thinking is getting better, you know, start to... not to forget that much any more. Just sit here and go for a little walk; that is not really the thing.*

[Marko; 70s; tablets; diagnosed 10 years]

Marko's comment highlights his perception of the benefits of physical exercise, not only on his diabetes and general physical health, but also on his emotional well-being and mental health. Marko also puts forward his own understanding of the cost-benefit analysis of having chronically-ill people in the community access physical activity programs: more exercise leads to better physical and mental health, which in turn might lead to less need for medication.

Later in the interview, Marko makes a comment which brings to the fore an issue affecting other participants, that of social isolation. Marko reflected on his lack of motivation to exercise at home, despite the fact that he had some exercise equipment in the house. Asked whether getting out of the house makes a difference, he promptly responds:

*Yeah, yeah. Talk to other people, not just to each other all the time, you know. We don't got any family and things like that... To communicate. We don't communicate with anybody... I would forget talking!*

[Marko; 70s; tablets; diagnosed 10 years]

Although Marko laughed off after his last remark, it was clear from this comment and from the rest of his narrative that both he and his wife felt very isolated in their suburb, where they had been living for five years after moving from a country town. Martin's account of his personal circumstances revealed a similar experience. Martin, who, like Marko, reported suffering from depression, makes a comment that sums up his state of mind:

*I'm alone from morning to night.*

As with most participants who had attended a structured diabetes education course, Martin had experienced a one-off session, with no follow-up. He suggested that the sessions should be held more often, inviting participants to attend other meetings and involving them in other activities, adding:

*You get the comfort of others in similar circumstances.*

[Martin; 60s; tablets; diagnosed 10 years]

The issue of social isolation and the role that community-based services might play in alleviating its impact was also brought up by Rose, who reported high levels of stress that impacted on her quality of life. During the interview Rose mentioned the comfort and emotional support she gets from visiting and talking with friends. At the end of the interview, when asked how services for people living with diabetes could improve, she reflects on those in the community who do not have support networks:

*People who are lonely, and who are living alone with diabetes, if people could be more... how should I say? More, uh... what's the word I'm looking for? More caring towards them, you know, keep an eye on them, you know, because they get very depressed, and depression, as I said, for diabetes, is not good. So if they could just, you know, be there for them, talk to them, visit them more often, you know, understand more, I think it would be better.*

Prompted as to whether she is referring to community nurses visiting people with diabetes in their homes, Rose promptly adds:

*That's the one! Yeah, yeah.*

[Rose; 60s; insulin; diagnosed 20 years]

Community nurses were also mentioned by Rose's husband, Michael, who was interviewed separately. Michael, who generally did not have a very positive opinion

of his medical care, reported having had a good experience with the community nurse who ran the diabetes course he attended in the mining town where he lived at the time of his diagnosis. When asked about how diabetes services could be improved, Michael reflects:

*I know that there's quite a lot of people having diabetes, but uh... you know, they should have... they should have like people... like surgeries, you know, all the surgeries should have a sort of specialist. [...]  
Community nurse even, you know, which is... in the bush, they have the community nurse, here they don't have, here. And a community nurse dealing with diabetes, comes and sees you, or makes an appointment, so you don't have to go all the way to [tertiary hospital]. She can help me, sort of thing; those kind of people.*

[Michael; 60s; insulin; diagnosed 15 years]

Similarly, Alison comments on the need for more local support services:

*Diabetes is quite prevalent in our society, uh... I feel that there should be, I don't know, some kind of... like, I understand that it all costs money and... but I think maybe there should be more suburban-based diabetic carers or nurse practitioners maybe, or people who are more diabetes-educated. I think there should be more available, that would be wonderful.*

[Alison; 50s; tablets; diagnosed for eight years]

As part of the support services for people living with diabetes, some participants pointed out the need to have more chemists registered with the National Diabetes Services Scheme (NDSS) in the community. Participants reported that there were only a small number of chemists in their local area which supplied diabetic products such as insulin, pens and injecting needles at subsidised prices as part of the NDSS scheme, which led to access issues. Patricia, who is on insulin, reported that she had had negative experiences with her local chemist. She recalls one incident with her faulty insulin pen:

*Patricia: I had one that kept jamming on me, and uh... it was one I was using at night-time, and they said, 'well, when you bring it in we'll give you a new one and if you don't bring it in we won't'. So when I took it over, 'oh, we haven't got any, you'll have to wait'. Three weeks I waited...*

*Interviewer: for the pen? So what did you do in the meantime?*

*Patricia: well, I had to keep using it and praying that it wouldn't jam. 'Cause when you try to get ten units of insulin and it keeps jamming on you, it takes a long time, and the bruises get quite big.*

Later, Patricia talks about her vision of having a NDSS-registered chemist in all shopping centres:

*So, really the biggest thing for me is... it would be that they... Diabetes Australia started letting all the chemists, the ones in the biggest shopping centres and that. So every shopping centre should have a chemist that can do it. So... because everyone's got to go out and do shopping.*

[Patricia; 60s; insulin; diagnosed six years]

Perceived issues with local chemists were also raised at the non-Indigenous focus group. Anne, who is on insulin and reported other co-morbidities, comments on the fact that used needles cannot be disposed of at any chemist:

*I feel I should be able to take that [needles] into any chemist shop, not just the one that sells diabetic products.*

[Anne; 50s; insulin; diagnosed 10 years]

Later, Anne added that although the pharmacy at one of the main tertiary hospitals sold diabetes products, they did not collect used needles. The issue of the safe disposal of used needles was also raised by other participants as part of the support systems to be improved in the community, as was addressing the poor hygienic conditions in which people who are on insulin have to inject themselves in public places.

## **Community education and awareness**

Another common theme to participants' narratives was the perceived need for more community education and awareness. Participants highlighted the need for more preventive work to be done in the community, especially among children and adolescents. Participants also gave a high priority to increasing the level of community awareness about the disease, in the community at large but also among health professionals and welfare services.

### **'Educate the kids'**

The main priority elicited by Aboriginal participants was the need to 'educate the kids'. This issue was raised in several occasions during the Indigenous focus group, and it was also raised during the interviews with Derbarl Yerrigan clients. There was a general consensus among Aboriginal participants that their children and particularly their grandchildren did not want to listen to them and learn from their

experience, and most participants expressed their fear that their ‘grannies’ (grandchildren) were going to ‘end up like them’, that is, developing diabetes. During the focus group, participants talked about the importance of encouraging their children to eat ‘the right food’ and take part in healthy activities such as sports. Renee and Nicole talk about their adult children:

*Renee: they don't listen when you're trying to tell your kids. Do you want to be like I am? I just tell them straight out, because they're doing the wrong thing now.*

*Nicole: and they just want you to finish talking so they just get on with whatever they're doing.*

Later in the focus group, when discussing changes to their diets, another exchange takes place between the same participants:

*Renee: well, I'm making my grannies eat a lot of fruit now, just fruit. So that's changing, for their benefit, for when they get older. That's what I'm saying.*

*Nicole: I reckon families have got to be educated.*

*Renee: well, you can be educated, but you can educate your kids too, as well.*

*Nicole: they're more interested in growing marihuana than diabetes.*

[Renee; 50s; dialysis; diagnosed 20 years. Nicole; 50s; tablets; diagnosed 10 years]

The exchange highlights some of the concerns that were commonly reported by Aboriginal participants as their main sources of stress: their worry about their children and grandchildren, and their concerns about drug and alcohol abuse issues affecting their families and communities. Indeed, the exchange between Renee and Nicole prompted all participants to join in and engage in conversation, suggesting that these were issues which were of concern to all.

This perception that there is a need for more education on diabetes needs to be understood in the context of the perceived need for more education generally, a common theme among Aboriginal participants. Gail, who took part in a joint interview, reflects on this issue:

*Well, I met some people the other day, and they couldn't read or write a letter. If they can't read or write, how are they going to survive in the world?*

Later in the interview, Gail adds:

*[...] especially Aboriginal people, there must be... trying to keep them in school longer. I mean, once they get to a certain age, 'I want to get out, mum, I want to get out'. Education is very important, and that's the most main thing in our lives.*

[Gail; 70s; insulin; diagnosed 20 years]

Although a strong theme among Indigenous participants, the need for more education on diabetes was also raised by non-Indigenous participants. Mandy, who was diagnosed with IGT several years before she developed diabetes, admitted to not knowing much about diabetes prevention, even though she knew she was at risk because of her family history. During the interview, Mandy came across as not being very articulate; her responses tended to be short and she did not elaborate much on her comments. However, as Mandy discusses the need for more education on diabetes, she provides a more detailed account, suggesting that this is something about which she feels strongly:

*Educate people better, you know, make them a lot more aware, yeah... [pauses as she reflects]. Yeah, education about it, yeah, or maybe starting in primary school, trying to educate the kids there, make them aware of uh... just make them aware of it, yeah... You know, is this going to happen to you? Yeah... 'Cause I know there's a lot of kids that sit in front of computers and just... 'cause I must admit my boys were the 'square eyes', but now they've grown up, but they had Nintendos and they would sit there... But only my oldest son is overweight, 'cause I told him he's at risk for it, 'cause he's overweight, yeah.*

[Mandy; 50s; tablets; diagnosed two years]

Mandy's account reveals her concern for her sons, in particular for one she perceives to be at higher risk because of his unhealthy weight. This concern for the next generation was common among participants, and shaped their views on the need for more preventive work to be done in the community. The need for education was also raised by Alison:

*Education, I think. I think educating, uh... like two... in two ways. I feel that there definitely should be more education about some of the reasons why people do develop diabetes, type 2 diabetes, because I uh... we now know that, apart from having the genetic predisposition, it is related to lifestyle, and I think that, I know there's a lot more out there about staying fit and healthy, and in a good weight range, but I think there should be, they should emphasise more that it can help prevent the type 2 diabetes. I think children should be taught this at a younger age, you*



*know, I think, even... 'cause even though my mother was diabetic, uh... I don't think I had enough information about it, but, you know, I think some of the factors that may have helped me were not really... I suppose driven home well enough for me, you know, so that type of thing I think would be very good. And I do think that education as well for, once people have the condition, that I think if it's known that it is actually quite a serious condition, and people do need some consideration when they've got it, uh... they need... you need understanding, and sometimes... sometimes you need absolute cooperation, you know, uh... especially if you're prone to hypo attacks you need to...*

[Alison; 50s; tablets; diagnosed eight years]

Alison's comments reflect similar views to Mandy's with respect to educating children at school, and her personal experience also echoes Mandy's with regard to her reported lack of information on how to prevent diabetes, even though she had a family history of the disease. Alison's comments also highlight another aspect of education which was also perceived as needed: raising the general awareness about diabetes in the community.

### ***Raise community awareness***

Most participants mentioned the need to raise community awareness about diabetes, which they hoped would lead to a better understanding of the disease and the requirements of its management. Participants' accounts revealed a shared perception that people around them and the community in general did not understand what they were going through, which they articulated as 'people don't understand' or 'they don't comprehend'. Participants' feelings and attitudes towards the perceived lack of understanding of those around them were discussed in Chapter 8; participants' views on the need to raise community awareness are presented here.

The issue of lack of community awareness was a strong theme in the non-Indigenous focus group. Reflecting on the hardest aspect of living with diabetes, Christine comments:

*Well, I've got neuropathy, and I have good days and bad days, and when I've got bad days, people don't understand why... you can't do this and you can't do that.... And I say well, I'd like to, but they can't comprehend [...] I feel like I have to keep explaining to people, I have good days and bad days; this is a bad day.*

[Christine; 60s; tablets; diagnosed 20 years]

Later in the focus group, Diane, a single mother of two, comments:

*There's nothing to be ashamed of having this disease, I mean, this is the thing. Having... you know what I mean, there's no shame in having diabetes, you know, like... that's the point... people out there who don't have it don't know... technically, they don't care. If it's not their family, if it's not them... they don't care... They see a diabetic, with a needle, it doesn't matter who you are, where you are... they think the same thing, you know. More awareness... because it takes the shame, I mean, I'm not ashamed of having diabetes. I'm sure these ladies aren't technically ashamed to have diabetes, it's not technically our fault... It's just more, you know, we want other people to know that.*

[Diane; 20s; tablets; diagnosed one year]

Diane appears to be at pains to explain that she is not ashamed of having diabetes, even though her narrative – punctuated by her frequent use of the words ‘shame’ and ‘ashamed’ – might suggest otherwise. Furthermore, Diane appears to blame this induced feeling of shame on the lack of community awareness about diabetes, and the stigma associated with needles and injecting, and calls for more awareness to break down pre-conceived ideas about the disease. Rose had similar views:

*I would like someone to be more understanding... people to be more understanding towards diabetics, and to be more patient with them. 'Cause some people just snap like that, you know, they think, 'oh, we're just putting it on, we just want attention...' It's not that! It's not that, they don't understand, you know, and uh... people to be more relaxed, more cheerful, more open, and talk about it, and say what you have to say, and, you know, listen to the other person, you know, and try and understand what they're going through, you know. It's not everybody that understands diabetics, no.*

[Rose; 60s; insulin; diagnosed 20 years]

Some participants raised the issue of the lack of awareness in specific settings, and the potential impact of this lack of awareness on the well-being of people living with diabetes. Sheryl mentioned that she was a member of a local RSL<sup>36</sup> club; when discussing ways in which the quality of life of people living with diabetes could be improved, she recalls a recent incident at her club:

*It's an education that everybody should know a bit about, because, like, not long ago, someone... one of the old blokes at the RSL collapsed down there, and no-one knew that he was diabetic, so, and... you know, they just didn't know what to do with him, they didn't know if he'd had a heart attack or whatever. But they've made it now that if you've got a medical*

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<sup>36</sup> Returned and Services League.

*problem like that, they'd like to know about it, so, they've got information on it, so... And they were at a real standstill there, so, I think, unless you're someone that knows, you are diabetic and you see something happens, you don't know what you're doing, you don't know what to treat, you know, you could be doing the wrong thing, so, yeah.*

[Sheryl; 60s; diet; diagnosed one year]

Finally, Jim and Rhonda raised the issue of the need for agencies working in the community to be better informed about the disease. They recalled a recent incident in their neighbourhood when a police officer had arrested a person on the suspicion of being under the influence of illicit drugs who was eventually found to be suffering from a hypoglycaemic episode. In addition, Jim and Rhonda highlighted the lack of awareness of diabetes generally, and of the dietary requirements of people living with diabetes in particular, among welfare agencies running food banks. Rhonda, who was timid and less articulate than her husband, was keen to make the following point, which encapsulates participants' views:

*I think the public; they should get to know about sugar diabetes.*

[Rhonda; 60s; tablets; diagnosed eight years]

## **Conclusion**

Participants called for accessible, community-based diabetes services, and more community education and awareness of their disease. Their vision of a diabetes support service in the community was a local, accessible one-stop centre where they could receive the support of their peers, and advice from diabetes-trained health professionals. Participants also highlighted the need for information on available services to be made available locally. Education on diabetes and a focus on prevention among children and adolescents were seen as a priority, as was raising the awareness of disease among the community at large, and health professionals and welfare agencies in particular.



## Chapter 11 – Discussion

*Inequities in how society is organized mean that freedom to lead a flourishing life and to enjoy good health is unequally distributed between and within societies.*

(Commission on Social Determinants of Health)

In this chapter, I discuss the main study results in the context of evidence from research conducted in Australia and overseas. I use the elements of Brown and colleagues' conceptual framework on the relationship between socio-economic position (SEP) and diabetes health outcomes (2004) to demonstrate the complex and multilayered way in which socio-economic disadvantage impacts on health and healthcare-seeking behaviours and the experience of disease more broadly, and hinders the ability to self-manage. Thus, I challenge the view that places the onus of effective diabetes management on individual behaviour, and present the experience of disease and disease management as embedded in the flow of everyday life.

In addition, I explore the applicability of the framework to a qualitative study of the lay experience of disease, and discuss a proposed modified framework incorporating the main pathways of disadvantage based on the study results.

### **Experience of diabetes: Pathways of disadvantage**

In this section, I explore the ways in which the mechanisms linking SEP and health outcomes among persons living with T2D operate by discussing the main study results as they relate to each of the elements proposed by Brown and colleagues in their conceptual framework (2004). Limitations to this approach are acknowledged; they are consistent with the limitations of the study design discussed in Chapter 4, and are primarily a result of the study's aim and objectives, and the methodology adopted. In accordance with its aim and objectives, the study explored the attitudes and experiences of persons living with diabetes, and thus, did not include the views of health professionals involved in diabetes care; in addition, the study results are based on self-reported data; and finally, limitations relating to the limited sample size are also acknowledged. These limitations restricted the exploration of some elements of the framework, and are discussed throughout this chapter as they arise.

I begin the discussion of results with the end-point element of the multilevel framework, that is, *health outcomes*, and continue upstream, from the *proximal factors* linking SES and health outcomes, to more upstream *distal factors*, concluding with the discussion of the results relating to the *socio-economic position* element, and a consideration of the *critical covariates* posited by Brown and colleagues (2004). For the reader's benefit, I present a summary of each element of the framework in each section (a detailed description of the framework is provided in Chapter 3).

## **Health outcomes**

The *health outcomes* element of the framework is highlighted in Figure 11.1; it includes general outcomes, such as health status, quality of life, and mortality; and diabetes-specific outcomes, both intermediate and long-term (Brown *et al.* 2004).

*It's a very depriving disease; as I said, if you get too much glucose in you, you become very tired, you become very lethargic, no sort of energy drive, so it just lets you in a state where you're tired, no energy. You just feel a slump on a chair; and that does, I guess, over a period of time, get worse and worse and worse... you know, getting up at 11 o'clock in the morning, falling asleep.*

[Peter; 50s; tablets; diagnosed seven years]

Results from this study suggest that participants' everyday lives were coloured by the deleterious effects of general and diabetes-specific quality of life and morbidity issues. Reports of fatigue – a highly sensitive marker of depression (Zimmerman *et al.* 2006) – were common, and participants' narratives suggested that fatigue was both a cause and a result of poor diabetes self-management, which is consistent with findings from a review of the literature on fatigue in patients with diabetes (Fritschi and Quinn 2010). There was also evidence of the negative impact of diabetes on emotional well-being, reported by participants as mood swings and feelings of frustration. Also common were reports of physical symptoms associated with *short-term complications* of diabetes, especially poor glycaemic control – commonly described as feelings of light-headedness and shakiness. All these symptoms impacted negatively on participants' perceptions of their *quality of life*, and support research showing that people living with diabetes report worse quality of life than the general population (Smith 2004).

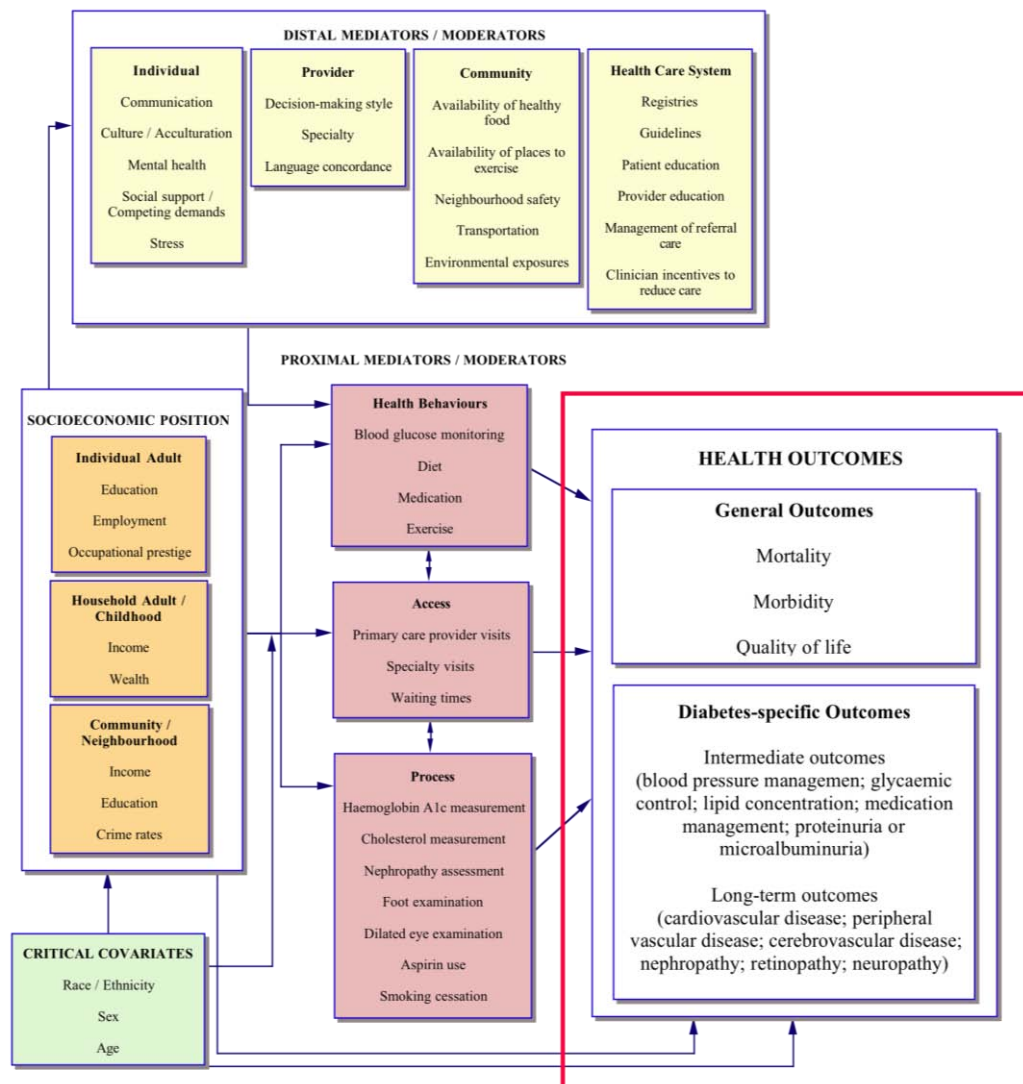


Figure 11.1: Conceptual framework for the link between SEP and health among persons with diabetes (health outcomes highlighted). Source: Brown and colleagues (2004).

Reports of *long-term diabetes complications* were common among participants, which is consistent with Australian (AIHW 2008b) and international (Bachmann *et al.* 2003) data showing higher levels of diabetes complications in low SES groups. In particular, reports of cardiovascular and cerebrovascular disease were common, supporting AIHW data indicating that 60 per cent of people with diabetes have at least one form of cardiovascular disease (Tong and Stevenson 2007). The high level of cardiovascular co-morbidity in this sample is of concern, as cardiovascular disease, especially hypertension, is one of the major causes of chronic kidney disease (Tong and Stevenson 2007). Eye problems were also common, with the majority of participants reporting a history of cataracts or glaucoma.

Consistent with Australian figures showing that people in the lowest SES groups are at higher risk of being overweight or obese (AIHW 2008b), *weight issues* were commonly reported. Participants' narratives also revealed high levels of non-diabetes-related *morbidities* including asthma, arthritis, lymphoedema and cancer. In addition, there were reports of injuries and joint (hip and knee) problems, which were in some cases aggravated by excess weight, and resulted in pain and mobility issues.

Overall, results from this study showed several indicators of poor *health status* impacting negatively on perceptions of *quality of life*, which is salient for people living with diabetes, because self-management affects virtually all aspects of daily life (El Achhab *et al.* 2008).

### **Proximal factors**

*Proximal factors* are the main mechanisms posited to influence the association between SEP and health outcomes. They can be mediators, if they are the means through which SEP influences health outcomes, or moderators, if the effect of SEP differs according to levels of the factor (Brown *et al.* 2004).

*It is very annoying when you go to your doctor and they say 'here's the diet sheet, off you go'... If you went there and said 'I'm an alcoholic, I need help', he wouldn't tell to go off and stop drinking, they'd be referring you on. And it is annoying when you are trying your best to lose weight and you can't, and you just get this...*

[Anne; 50s; insulin; diagnosed 10 years]

This element of the framework is highlighted in Figure 11.2, and includes three distinct domains: *health behaviours*, *access* and *process*. The *health behaviours* domain relates to lifestyle and clinical self-management, and is thus aligned with one of the objectives of the study explored in Chapter 7. The remaining two domains, *access* and *process*, relate to the medical management of diabetes, and are aligned with another objective of this study explored in Chapter 9. Here, I discuss the main study results relating to each of the three domains separately.



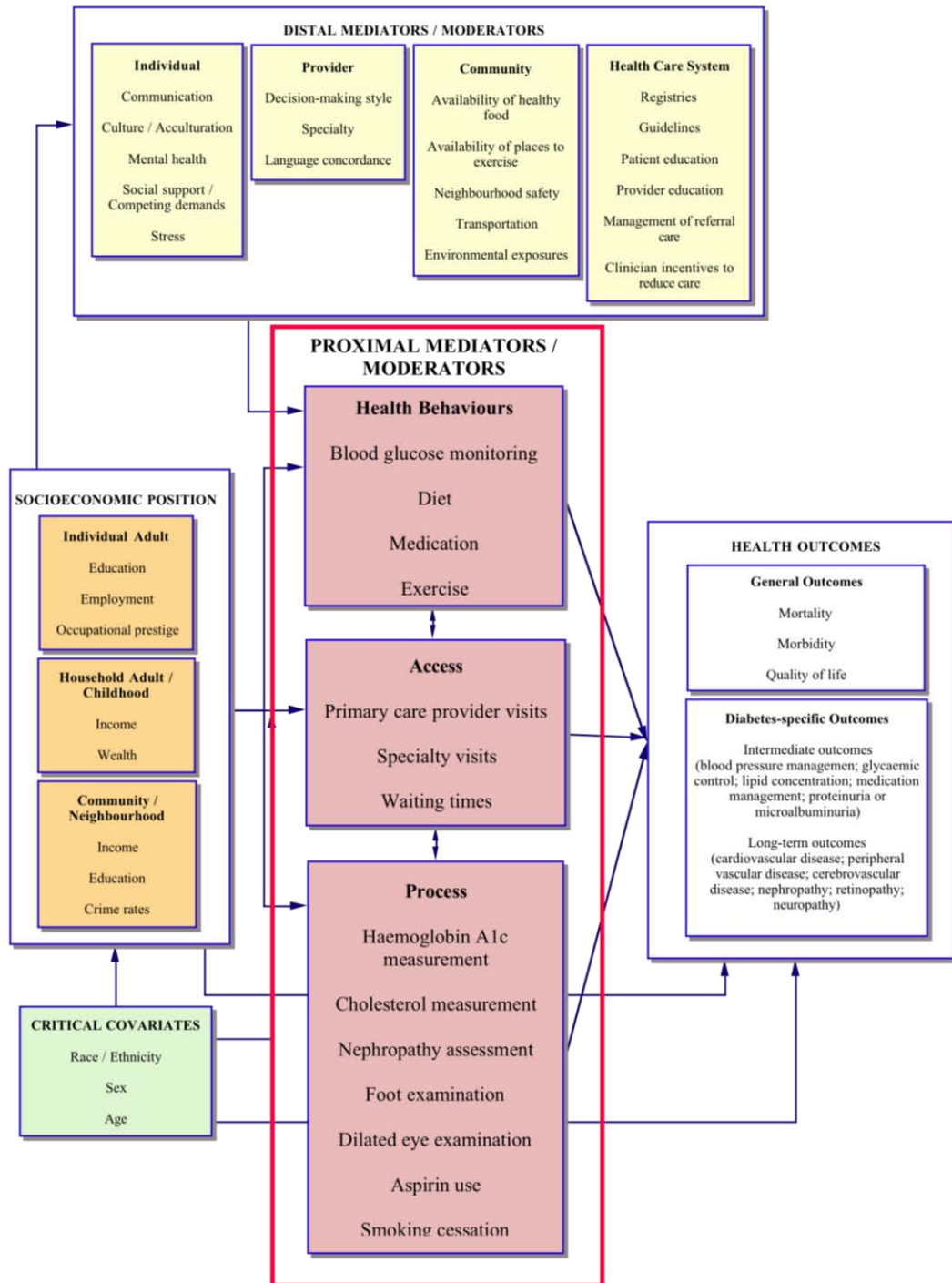


Figure 11.2: Conceptual framework for the link between SEP and health among persons with diabetes (proximal factors highlighted). Source: Brown and colleagues (2004).

## Health behaviours

Results from this study suggest that participants viewed having a healthy *diet* as the main component of diabetes self-management. Participants generally demonstrated a good understanding of the requirements of a healthy diet, but could not always translate this knowledge to their everyday lives. Consistent with other research

carried out in Australia (Lupton 2000), there was evidence of the socio-cultural influences on food preferences and habits, as participants associated meals with memories, celebratory occasions and the delight of family gatherings. In this context, family meals and social outings were experienced as a challenge to self-control. Participants also revealed their emotional relationship with food; in particular, they reported turning to certain foods in moments of stress, which is of special significance in this sample of low income earners as high levels of stress were commonly reported.

There was evidence of access issues and food insecurity. Consistent with Australian data from research carried out among Aboriginal people living with diabetes (Abbott *et al.* 2010), women living in low SES areas (Inglis, Ball, and Crawford 2005) and people affected by chronic illnesses including diabetes (Jeon *et al.* 2009), the high cost of healthy food was commonly reported as a barrier to healthy eating. In addition, issues of food insecurity and lack of control over food were reported, especially among Aboriginal participants, with several reporting relying on others for food provision and meal preparation, which is consistent with findings from Abbott and colleagues (2010). Results from this study highlight the limitation of regarding eating as a behaviour under the control of an individual, a view which ‘exaggerates the extent to which rational choice drives what people choose to eat, and underestimates the extent to which eating is embedded in the flow of day-to-day life’ (Delormier, Frohlich, and Potvin 2009, 217).

Although *exercise* was perceived as an important aspect of self-management, very few participants reported engaging in regular physical activity. This low engagement needs to be understood in the Australian context, where it is estimated that 63 per cent of the adult population are not undertaking sufficient physical activity (AIHW 2010), and overall physical activity levels are slightly lower among people with diabetes (AIHW 2008b). Consistent with UK research conducted among Pakistani and Indian immigrants living with diabetes (Lawton *et al.* 2006b), exercise was framed in a negative way, and the emphasis was on the barriers involved. Lack of motivation, cost involved and neighbourhood safety concerns were reported as barriers to exercise, and participants also cited the existence of co-morbidities as hindering exercise, supporting US research involving urban Latinos (Caban *et al.* 2008), and findings from Lawton and colleagues (2006b). The main strategy to

overcome lack of motivation was seen to be exercising in a group setting, which was perceived to provide social and emotional support from peers; some participants wished for accessible community-based walking groups, which have been shown to be effective in increasing physical activity among people living with chronic diseases in a low SES area in Perth (Lishman 2003), and among Pacific Islanders living in diabetes in NSW (Oliver *et al.* 2007). Results from this study highlight the interplay of multilevel factors influencing this aspect of self-management, which include domains of *health outcomes* (existence of co-morbidities), *distal individual factors* (lack of motivation), *distal community factors* (neighbourhood safety), and *socio-economic status* (costs involved).

With regard to *medication*, taking hypoglycaemic agents was experienced as a routine to which most participants seemed adjusted; however, there were reports of forgetting to take the prescribed medication, and some participants reported resorting to strategies and prompts, which is consistent with data from research conducted in the US (Nagelkerk, Reick, and Meengs 2006), while there was some evidence of the role of spousal support in enabling adherence, supporting data from US research conducted among urban Latinos (Caban *et al.* 2008). In contrast with US research, where the cost of medication has been shown to be one of the main barriers to self-management for people living with diabetes (Nagelkerk, Reick, and Meengs 2006), there was little evidence that cost was a barrier to adherence to medication regimens; however, the cost of multiple medications was of concern to some participants, which supports data from a study conducted among people with diabetic kidney disease in Australia (Williams, Manias, and Walker 2008).

The experience of clinical self-management was markedly different for participants who reported being on an insulin regimen, as their accounts were dominated by their dislike of needles and injecting, and the negative impact on their daily lives, especially for those who reported injecting several times a day. For those who reported not being on insulin, injecting elicited sentiments of fear and avoidance; and a common theme to all participants regardless of their medication regimen was the perception of the social stigma associated with needles. Results from this study are consistent with data from the cross-national *DAWN* study, which showed substantial resistance to insulin therapy among people living with T2D not taking insulin (Peyrot, Rubin, Lauritzen, Skovlund *et al.* 2005), and a review of the literature

published between 1985 and 2007, which identified social stigma, lifestyle adaptations and restrictions, and attitudinal barriers such as fear of injections as the main causes of psychological insulin resistance (Brod *et al.* 2009).

Only 14 participants reported performing *self-monitoring of blood glucose* (SMBG) regularly, and most reported that the frequency had decreased over time. Stable readings, reliance on physical indicators of hyperglycaemia, and avoidance were reported as reasons to either discontinue or reduce the frequency of SMBG, which is consistent with results from a longitudinal qualitative study conducted in the UK (Peel, Douglas, and Lawton 2007). These attitudes need to be understood in a context of clinical uncertainty about the efficacy of SMBG in patients with T2D (Peel, Douglas, and Lawton 2007); research conducted in Australia using data from the Fremantle Diabetes Study has shown no significant difference in HbA<sub>1c</sub> levels (Davis, Bruce, and Davis 2006) or improved survival (Davis, Bruce, and Davis 2007) between SMBG users and non-users.

### **Access to care**

*Regular access to general practitioners* (GPs) was reported by most participants; however, the frequency of visits varied, and was influenced by the need to obtain medication prescriptions for diabetes and other co-morbidities, and by the investigation and follow-up of diabetes complications and other health issues. Despite the fact that, in Australia, people with diabetes are more likely to seek the advice from allied health professionals (AHPs) than people without diabetes (AIHW 2008b), in this study evidence of access to AHPs – including podiatrists, dieticians and physiotherapists – was very limited, supporting Australian data showing significant inequities in the use of non-medical services (Korda *et al.* 2009).

With regard to *specialist care*, only participants on an insulin regimen reported seeing a diabetes specialist, generally once a year. In addition, there was strong evidence of regular access to ophthalmologists – particularly for those who reported a history of cataracts or glaucoma – which is consistent with data from the *BEACH* project<sup>37</sup> showing that referrals to ophthalmologists are the most common referrals for patients with T2D in Australian general practice (Charles, Ng, and Miller 2006).

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<sup>37</sup> Bettering the Evaluation And Care of Health (BEACH) project: continuous national study of general practice activity in Australia.

Perceived need influenced healthcare-seeking behaviour; this was high for eye care and, in contrast, low for podiatry services, and is a reflection of the low awareness of the importance of the care of feet and diabetic podiatry among participants. This finding is consistent with data from a population-based study in Europe which found low levels of education about the care of feet, particularly among people at highest risk of foot complications, such as those in low SES groups (De Berardis *et al.* 2005).

Previous negative experiences of episodes of care – related or unrelated to diabetes – also influenced healthcare-seeking behaviour, and sometimes lead to ‘doctor shopping’ or resulted in stopping accessing healthcare services altogether. Negative experiences of care elicited emotive responses from participants, and there was some evidence to suggest that some participants felt discriminated on the basis of their low SES, which impacted negatively on their attitudes towards healthcare services and medical professionals. This finding contrasts with research conducted in the US which found that although perceived ethnic discrimination was significantly associated with poorer medical diabetes management, perceived economic discrimination was not (Ryan, Gee, and Griffith 2008).

In this study, cost was not found to be a barrier to accessing GPs, as all participants reported accessing doctors who bulk-billed Medicare; however, cost was a strong barrier to accessing any healthcare service incurring out-of-pocket expenses, in particular AHPs. Consistent with findings from an Australian study on the economic hardship associated with managing chronic illness (Jeon *et al.* 2009), results from this study showed that participants had to make choices between expenditure for health care and other everyday expenses. Travel costs involved in accessing healthcare services were moderated by participants’ eligibility for subsidised transport, and, in the case of Derbarl Yerrigan clients, by tailored transport arrangements; however, the cost of fuel, parking fees, and the difficulties involved in negotiating public transport for those who did not have access to a car were cited by participants as being of concern.

In Australia, as a reflection of their poorer health status, Indigenous people access healthcare services at higher rates than non-Indigenous people, although this greater healthcare use does not match their greater care needs (AIHW 2008a; SCRGSP

2009). In this study, Derbarl Yerrigan clients reported a more accessible, coordinated and comprehensive model of diabetes care, including frequent access to podiatry services and regular medication reviews. This finding suggests that Derbarl Yerrigan's healthcare service provision is better aligned with the recommended diabetes model of care (WADoH 2008; Diabetes Australia 2010).

### **Process of care**

This domain relates to the quality of diabetes care, and refers to both technical and interpersonal factors (Brown *et al.* 2004); thus, it encompasses technical or clinical quality, and service quality (Tabrizi *et al.* 2008). As a consequence of the central role played by GPs in the management of diabetes, participants' perceptions of the quality of their care overall tended to be based around their views of their GPs. Supporting other research carried out in Australia among people living with chronic diseases (Infante *et al.* 2004), the construct of the 'good doctor' was a common theme among participants, and was used to describe an understanding, accessible and caring health professional. Participants in Infante and colleagues' study – mainly recruited through consumer organisations – based their views on quality of care not only on interpersonal, but also on clinical skills (Infante *et al.* 2004); in contrast, participants in this study had limited knowledge about the technical aspects of their care and, as a result, their views tended to be formed around personal characteristics.

Participants' attitudes and expectations of the quality of their care were shaped by their perceptions of the role of doctors in the management of diabetes, and were associated with their reported levels of glycaemic control. Thus, although a sense of personal responsibility about their disease was common among participants, those who reported good glycaemic control tended to accept the role of GP as being limited to prescribing medication, while those who reported poorer glycaemic control and health outcomes tended to display despondency towards medical professionals, whom they perceived as taking little interest in their condition. Consistent with research carried out in the UK (Pooley *et al.* 2001) and Australia (Kokanovic and Manderson 2006), and contrasting with findings from Tabrizi and colleagues (Tabrizi *et al.* 2007), time constraints underpinned most concerns relating to quality of care, and most participants experienced their medical encounters as being rushed and leaving little time for meaningful communication.

Views on diabetes specialists were influenced by participants' perception of the systemic inefficiencies affecting the healthcare system, and lack of continuity of care was highlighted as the main concern, which is consistent with findings from Pooley and colleagues (2001). Supporting findings from a small sample in regional Victoria (Wellard, Rennie, and King 2008), participants' views on AHPs, in particular dieticians and podiatrists, were ambivalent and suggested lack of trust and scepticism, and highlighted participants' limited understanding about the role of allied health services in diabetes care.

### ***Distal factors***

*Distal factors* are mediators and moderators of the relationship between SEP and diabetes health outcomes; they act through their relations to proximal factors and operate on four levels: individual, provider, community and healthcare system (see Figure 11.3) (Brown *et al.* 2004). Here, I present the main study results relating to each level of influence separately.

*Worry... worry; yeah, that's what kills you.*

[Frances; 70s; tablets; diagnosed 40 years]

### **Individual-level factors**

Results from this study suggest that *communication* with healthcare professionals may influence health and healthcare-seeking behaviour, and perceptions of quality of care. Participants who reported good communication with their GP tended to be satisfied with the quality of their care and report good metabolic control; conversely, participants who were unsatisfied with their healthcare provider's communication style tended to be unsatisfied with their care and report poorer outcomes. Derbarl Yerrigan clients, however, while holding their GP in high esteem and reporting being inclined to follow her recommendations, generally reported poor glycaemic control and poor health status, suggesting that medical care is necessary but not sufficient to ensure good diabetes outcomes.

The level of health literacy was generally low among participants; a low level of health literacy may be a barrier to effective communication with health professionals, and has been associated with poor glycaemic control (Schillinger *et al.* 2002). In particular, participants demonstrated very limited skills regarding two key abilities

identified as important in seeking, understanding and utilising health information: knowing ‘when’ to seek it and knowing ‘where’ to seek it (Jordan, Buchbinder, and Osborne 2010).

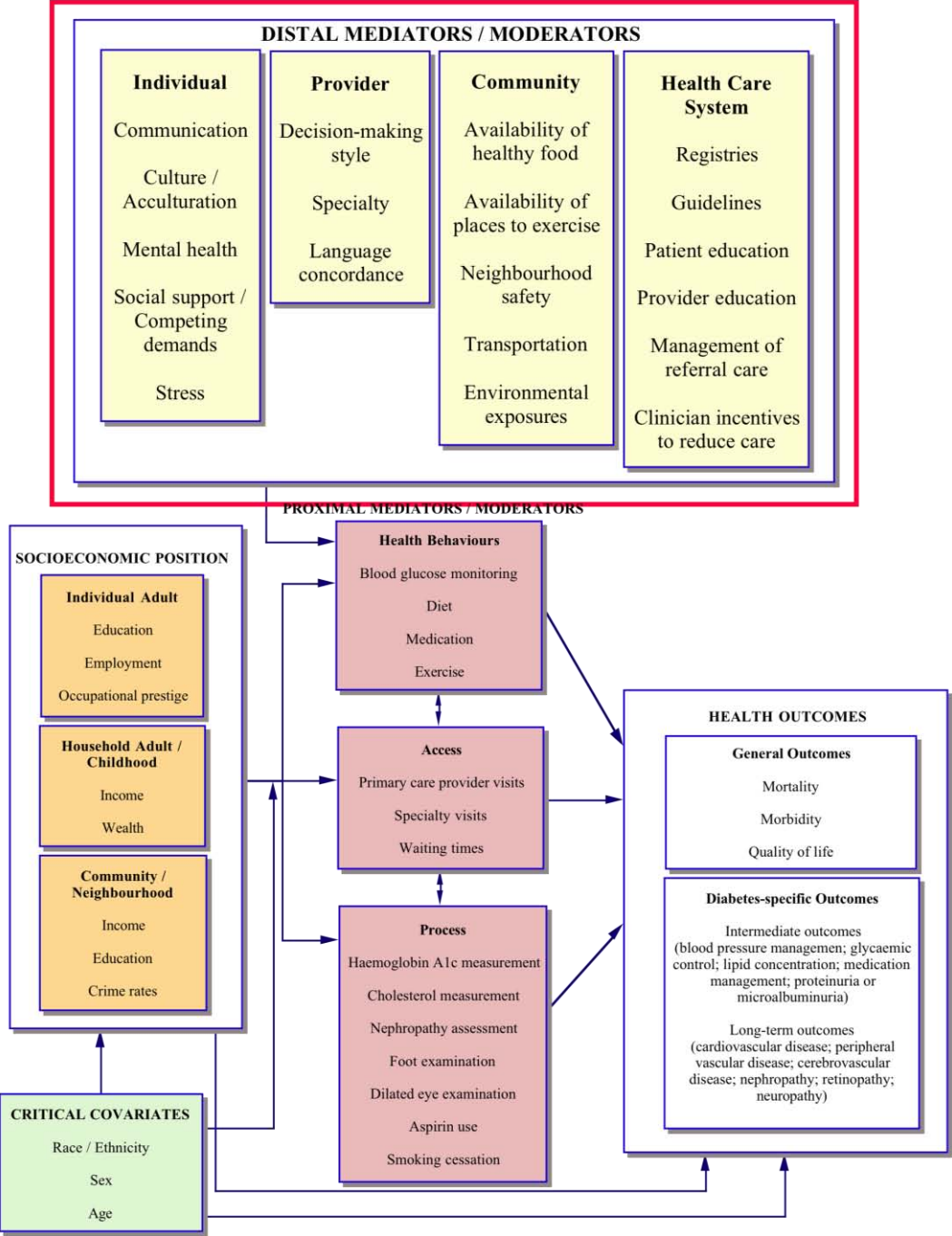


Figure 11.3: Conceptual framework for the link between SEP and health among persons with diabetes (distal factors highlighted). Source: Brown and colleagues (2004).

Results showed a strong influence of *cultural factors* on health beliefs, attitudes towards self-management and healthcare-seeking behaviours. In particular, there was strong evidence of the socio-cultural dimensions of diet and eating: shared norms



shaped food preferences and dietary habits, and underpinned the value attached to the social role of meals in family gatherings. Findings on the cultural dimension of food and eating are consistent with research carried out in the US among urban Latinos (Caban *et al.* 2008), and in Australia among rural Australian couples (Lupton 2000), and support the view that although eating involves individual choices, these are conditioned by the context in which they occur (Delormier, Frohlich, and Potvin 2009). Furthermore, this study found some evidence of the impact of *acculturation* – the changes that occur when different cultural groups come into intensive contact and one of the societies is more powerful than the other (Ember, Ember, and Peregrine 2005) – on dietary habits among Indigenous participants. There was a common perception that the change from a traditional diet ('bush tucker') to a Western diet had impacted negatively on Indigenous health and well-being, as explored by O'Dea in her seminal study of temporarily reversing the urbanization process among a sample of Aboriginal Australians living with diabetes (1984). This finding supports those by Abbott and colleagues on the social, financial, health, and historical barriers to dietary change faced by Aboriginal people (Abbott *et al.* 2010).

There was evidence of the impact of *mental health* issues on participants' experience of disease. Although participants were not prompted to discuss their mental health, two participants reported having been diagnosed with depression, and three reported having consulted a psychologist, among them one female participant who disclosed experiencing suicidal ideation triggered by her inability to cope with the demands of the complex management of her multiple conditions. Furthermore, another participant reported that both her husband and daughter had mental health issues. Participants whose narratives included references to mental health issues tended to report high levels of stress, demonstrate lack of motivation with regard to self-management, and report poor health outcomes, which is consistent with results from the Fremantle Diabetes Study showing an association between depression, and physical inactivity and diabetes complications (Bruce *et al.* 2005).

Results from this study highlight the role played by other factors not addressed by the framework by Brown and colleagues (2004), such as self-efficacy and coping skills, which, in addition to mental health, may be considered as part of a broader domain of *psychological well-being*. Participants' narratives suggested different levels of self-efficacy with regard to self-management behaviours, and self-efficacy

was generally very low among participants with regard to physical exercise. The narratives of some participants suggested strong coping skills, high levels of resilience, coupled with a positive outlook on life, which was found to be an effective strategy for diabetes self-management in a US study (Nagelkerk, Reick, and Meengs 2006). These characteristics may act as a moderator of the influence of SES on health outcomes, helping people to cope with the demands and unpredictable results of diabetes management, which often lead to what has been termed ‘diabetes overwhelmus’ (Rubin 2001, 55).

There was evidence that *social networks* impacted on participants’ experience of disease and played a dual role, enabling and hindering self-management. Consistent with data from a UK study (Stone *et al.* 2005), close relatives with diabetes were seen as sources of emotional and informational support. In general, findings from this study showed that social networks were perceived as valuable sources of all four types of social support identified by Berkman and Glass: instrumental and financial, informational, emotional and appraisal (2000). These results are consistent with quantitative research conducted in the US among African Americans living with diabetes which found that those who were more satisfied with the social support they received reported experiencing a better quality of life, and that positive support was a predictor of physical activity and having a healthy eating plan (Tang *et al.* 2008). However, there also evidence that social ties were the source of competing demands, exacerbating high background stress levels. Consistent with data from a US study of African American women (Carter-Edwards *et al.* 2004), and from Australian research conducted among immigrant women (Kokanovic and Manderson 2006), there were ambivalent accounts of support from family members, and perceived lack of understanding from others triggered feelings of frustration and resulted in poorer perceptions of quality of life, which, in turn impacted on self-efficacy and coping skills.

This study yielded evidence of the strong influence of *stress* on diabetes management. Participants in this study reported high levels of stress, and their narratives suggested that living with diabetes was only one of many concerns in their lives, supporting findings from a US study comparing the profiles of people with good and poor glycaemic control (Savoca, Miller, and Quandt 2004). In particular, stress and worry featured very strongly in the narratives of Indigenous participants,

which is consistent with quantitative (Davis *et al.* 2007) and qualitative data (Thompson and Gifford 2000) from studies conducted among Indigenous populations in Australia. Overall, participants' lives were characterised by the existence of multiple stressors, which included life crises, financial concerns, and the inability to fulfil social roles. Competing family responsibilities, in particular caring for and worrying about children and grandchildren, were identified by participants as the main source of stress, and there was evidence in the narratives of Indigenous participants that flexible household arrangements and lack of control increased stress levels and negatively impacted on self-management routines, which is consistent with findings from Abbott and colleagues (2010). Participants' narratives also revealed high levels of stress and fear around their understandings of the physical decline associated with disease progression and diabetes complications, supporting data from research conducted among immigrant Australians (Manderson and Kokanovic 2009).

Results from this study suggest that participants' *family history of diabetes* may be an additional domain not addressed by the framework by Brown and colleagues (2004) operating at an individual level to influence health and healthcare-seeking behaviours. Most participants in the study reported that diabetes ran in their family, and their narratives indicated that this experience of diabetes as a family disease shaped their attitudes towards diabetes causation and progression, and their fear of disease progression and diabetes complications, which in turn affected their attitudes towards self-management. Results suggest that participants attributed the onset of disease to heredity rather than lifestyle factors, and thus, did not perceive themselves as being responsible for their disease. These results are partially consistent with findings from UK research comparing the accounts of causality of Pakistani and Indian immigrants and British-born respondents, although the authors found that British-born participants tended to attribute their disease to lifestyle factors (Lawton *et al.* 2007), whereas in this study attribution to heredity was consistent across all participants.

Despite the attribution of disease to heredity, participants generally regarded the management of disease as 'up to them', in contrast with UK research showing that participants who saw the onset of their condition as being outside of their control tended to surrender their responsibility and rely on health professionals for the

management of their diabetes (Parry *et al.* 2006). Participants in this study also demonstrated a strong sense of inevitability and fatalism about their disease, which is consistent with international (Stone *et al.* 2005) and Australian data (Kokanovic and Manderson 2006; Thompson and Gifford 2000) from studies conducted among vulnerable populations. Supporting Australian research among immigrant populations (Kokanovic and Manderson 2006) family history was found to strongly influence participants' fear of diabetes complications, exacerbating stress levels and impacting on self-management behaviours.

### **Provider-level factors**

Provider-level factors relate to the impact of health professionals' perceptions of their clients' SES characteristics on their relationship with their clients. As this study explored the experience of diabetes from the perspective of the person living with the disease, this domain could not be explored; however, participants' perceptions of their GP's decision-making and communication style were addressed under two domains: *process* (proximal factors) and *communication* (individual-level distal factors).

### **Community-level factors**

Results from this study suggest that although availability of *healthy foods* was not a barrier to self-management, accessibility had a strong influence on dietary patterns. In contrast with US research showing disparities in the availability of healthy food in poorer neighbourhoods (Horowitz *et al.* 2004), participants in this study did not report lack of availability of healthy foods. However, both physical and cost barriers to access were mentioned. In Australia, research conducted in Brisbane has shown little or no difference in price and availability of healthy food on the basis of area SES (Winkler, Turrell, and Patterson 2006), while in Adelaide the cost of recommended healthy food items has been shown to be lower in low SES suburbs (Tsang *et al.* 2007). However, this needs to be understood in the context of the rising cost of healthy food in Australia (Harrison *et al.* 2010), which disproportionately affects families on welfare or on single incomes (Tsang *et al.* 2007), as was the case with participants in this study. Physical barriers to accessing healthy food were also reported and are interrelated with the domain of *transportation*. Several participants reported relying on family members for transport to shopping centres as they did not have easy access to either a car or public transport. People living in low SES areas

might be more susceptible to physical barriers to healthy food, as a study conducted in Melbourne showed that more advantaged areas had closer access to supermarket while less advantaged areas had close access to fast food outlets (Burns and Inglis 2007). Concerns over transportation also influenced access to medical appointments.

In this study, despite the availability of *places to exercise*, cost was reported as a barrier to accessing recreational facilities; and *neighbourhood safety* concerns were reported as a barrier to walking as a form of exercise. Results from this study support US research showing that individuals living with diabetes who report fewer neighbourhood problems are more likely to engage in physical activity (Gary *et al.* 2008), and research conducted in the Perth metropolitan area showing that the influence of individual and social environment outweighs the role played by physical environment determinants, suggesting that access to recreational facilities is necessary but insufficient to achieve recommended levels of physical activity in the community (Giles-Corti and Donovan 2002). Furthermore, there was evidence to suggest that concerns about neighbourhood safety also impacted negatively on stress levels and, thus, on participants' perceived quality of life.

Results from this study did not show strong evidence of the impact of *environmental exposures*, and concerns about this issue were raised by one participant only.

### **Healthcare system-level factors**

Results from this study suggest that several characteristics of the Australian healthcare system generally, and of the organisation of diabetes care in particular, may pose greater obstacles for people of low SES. The accessibility and content of *diabetes education* was found to influence self-management behaviours. Despite research showing that people who attend diabetes self-management education (DSME) are significantly more likely to engage in preventive care measures and significantly less likely to engage in health risk behaviours potentially leading to diabetic complications (Strine *et al.* 2005), results from this study showed that access to DSME was inconsistent, with half the sample reporting never having attended structured DSME and having instead received limited counselling on self-management from their GPs. In addition, participants' accounts suggested that the information received was useful but overwhelming, and was inadequate to participants' needs and sometimes led to negative unintended consequences.

In this study, *financial and organisational arrangements* strongly impacted on access to diabetes care, both positively and negatively. Australia's universal health insurance scheme provides for free treatment by medical practitioners who choose to direct-bill (bulk-bill) Medicare Australia for any service rather than issuing a patient with an account (AIHW 2010). Thus, cost was not found to be a barrier to access to GPs – as all participants reported accessing a GP who bulk-billed – but it was found to be a barrier to accessing AHPs, in particular podiatrists, as the financial arrangement involves patient co-payments, unless a referral is made by a GP under a General Practice Management Plan (GPMP) (Diabetes Australia 2010). Participants reported little awareness of GPMPs and the health services that could be accessed through them, and thus relied on proactive case management by their GPs. It has been pointed out that due to the complexity of the arrangements of the Australian healthcare system patients often find themselves with out-of-pocket expenses (Jeon *et al.* 2009), which places an disproportionate burden on disadvantaged groups.

Lastly, data from the study yielded some evidence that suggested *lack of coordination* between specialists treating diabetes and co-morbidities such as cardiovascular disease; this lack of coordination may have more salience for people in low SES groups as they are more likely to have long-term diabetes complications.

### ***Socio-economic position***

In the framework by Brown and colleagues, *Socio-economic position* encompasses the structural location of individuals in a society, and the cumulative effects of time (2004). This element refers to individual SES, including characteristics such as income, education and occupation, but also community characteristics, such as area-level income, education and crime rates (see Figure 11.4).

*I get \$10,000 a year, and I've got to pay everything with my \$10,000. I can't afford to go to the exercises, or anything; just the essential things, buy food and pay the bills, the electricity and all insurances. And money doesn't go any way, what a pensioner gets today.*

[Marko; 70s; tablets; diagnosed 10 years]

In this study, common variables of education, occupation and household income were used to provide an indication of participants' SES, thus incorporating measures from the framework's *individual* and *household* domains. Here, I discuss the main study results relating to *individual/household* and *community SES* separately.

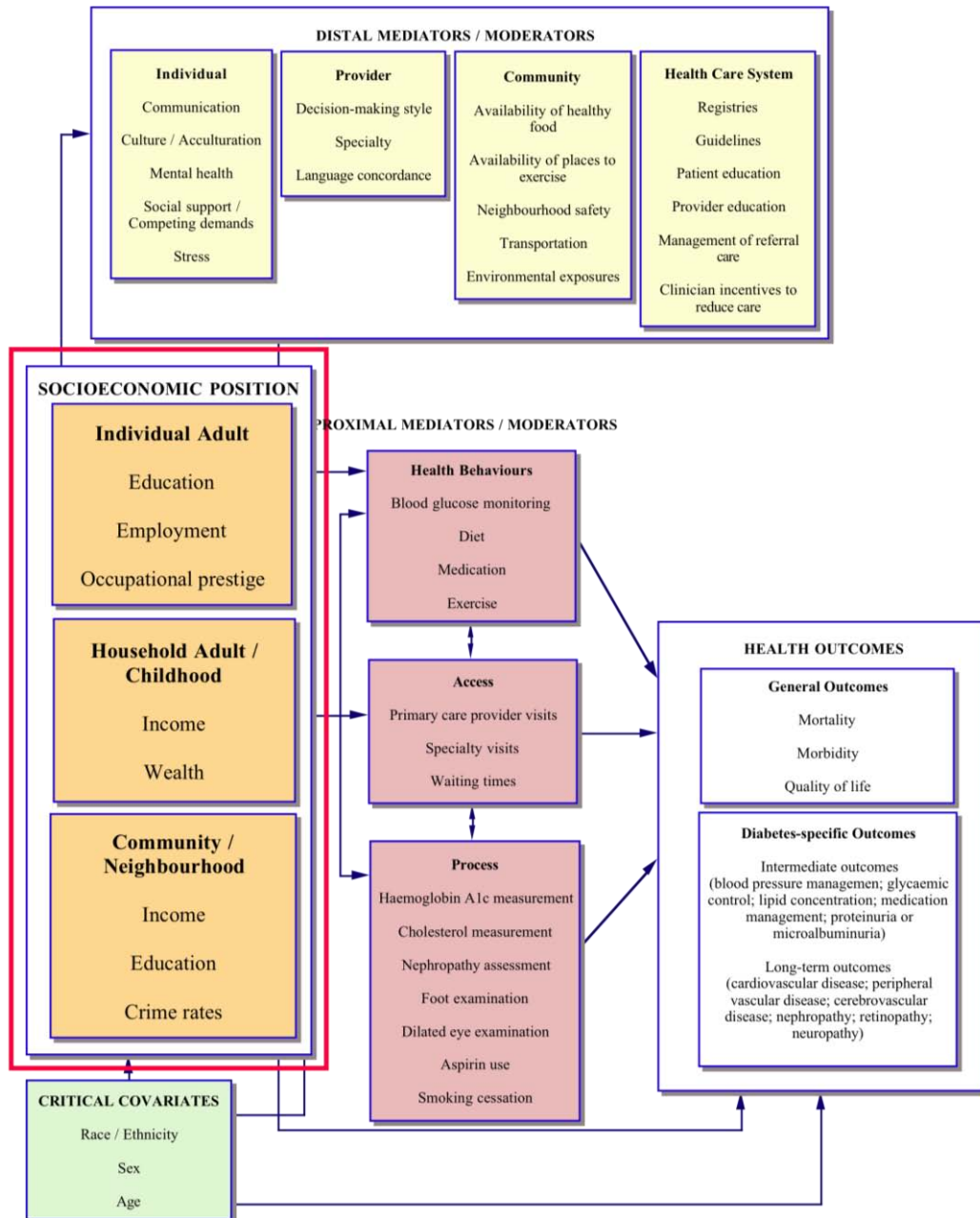


Figure 11.4: Conceptual framework for the link between SES and health among persons with diabetes (socio-economic position highlighted). Source: Brown and colleagues (2004).

### Individual/household SES

*Income* levels were very low among participants, with most reporting being either on aged or disability pensions, or on unemployment benefits. Living on low, fixed incomes coloured participants' experience of disease, and directly impacted on *proximal factors*, in particular on self-management behaviours. The link between SES and health outcomes operated through a proximal factor pathway by creating a cost barrier to purchasing healthy food and engaging in physical activity. Cost was found to be a barrier to healthy eating, highlighting that 'low income is a powerful

driver of food choice' (Brimblecombe and O'Dea 2009, 550). This finding supports Australian research showing that low SES groups are less likely to purchase and eat recommended foods (Turrel *et al.* 2002; Inglis, Ball, and Crawford 2005), with perceived high cost of healthy food being reported as a major barrier to healthy eating (Inglis, Ball, and Crawford 2005), and household income a stronger discriminator of healthy food purchase than education (Turrel *et al.* 2002). Cost was also found to be a barrier to physical activity and joining social activities, which is consistent with qualitative research into the economic hardship associated with chronic disease in Australia (Jeon *et al.* 2009). Overall, living on low incomes led participants to have to make everyday choices in the context of their limited resources, lending support to Jeon and colleagues' finding that economic hardship compromises people's healthy lifestyle choices (2009). In contrast with data from research carried out in the US (Nagelkerk, Reick, and Meengs 2006; Utz *et al.* 2006), in this study cost was not found to be a barrier to adherence to medication, although the cost of multiple medications was of concern, which is consistent with findings from research conducted in Australia among people living with diabetic kidney disease (Williams, Manias, and Walker 2008), and chronic disease (Jeon *et al.* 2009).

Participants in this study reported low levels of *education*, which were found to operate through influencing the *proximal* domains of *health behaviours* and *access*. Low levels of literacy increased the number of 'information barriers' – which have been identified as one of the socio-economic barriers to diabetes self-care (Rose 2005) – and negatively impacted on participants' awareness of the importance of specific aspects of their self-care and of the availability of healthcare and support services.

Finally, there was some evidence of the influence of *occupation* on health status and self-management behaviours. Although only one participant reported being employed at the time of data collection, participants' narratives revealed that most had been formerly employed in physically-demanding occupations, exposing them to a higher risk of injury. In addition, several participants reported that they had retired on health grounds, and some cited diabetes as the sole reason, pointing at the bi-directional relationship between low SES and poor health outcomes. There was also some evidence to suggest that the physical demands of manual work may influence



eating habits relating to portion size and energy content, which are difficult to break after a person ceases work.

### **Community SES**

The main sampling area was purposively selected on the basis of its high index of socio-economic disadvantage (see Chapter 5). As the focus of this study was on individual-level characteristics, the impact of area-level SES on the experience of disease was not fully explored; however, there was evidence to suggest that perceived and actual *crime levels* influenced perceptions of neighbourhood safety, which in turn impacted negatively on perceptions of quality of life and stress levels, and on attitudes towards physical activity.

### **Critical covariates**

Critical covariates are characteristics such as race/ethnicity, sex and age which may operate independently from SES and exert an influence on health outcomes (Brown *et al.* 2004). They are highlighted in Figure 11.5.

*Our history is bad for the disease, you know... the sugar disease. And it's all through the drink that kills lots of my family. Probably if I was a drinker I wouldn't be here today... they couldn't even reach 50. But I'm here, I'm 54, so, you know, I've passed that date because I wasn't a drinker.*

[Renee; 50s; dialysis; diagnosed 20 years]

### **Race/ethnicity**

Results from this study suggest that *ethnicity*, more specifically Indigenous status, operates independently from SEP to explain inequalities in diabetes health outcomes, pointing to the distinct, multi-dimensional nature of Indigenous poverty (Walter and Siggers 2007), and supporting data from a study of socio-economic gradients in self-reported diabetes for Indigenous and non-Indigenous Australians which showed that despite the marked gradient in both groups, Indigenous Australians had higher prevalence across all SES groups (Cunningham 2010).

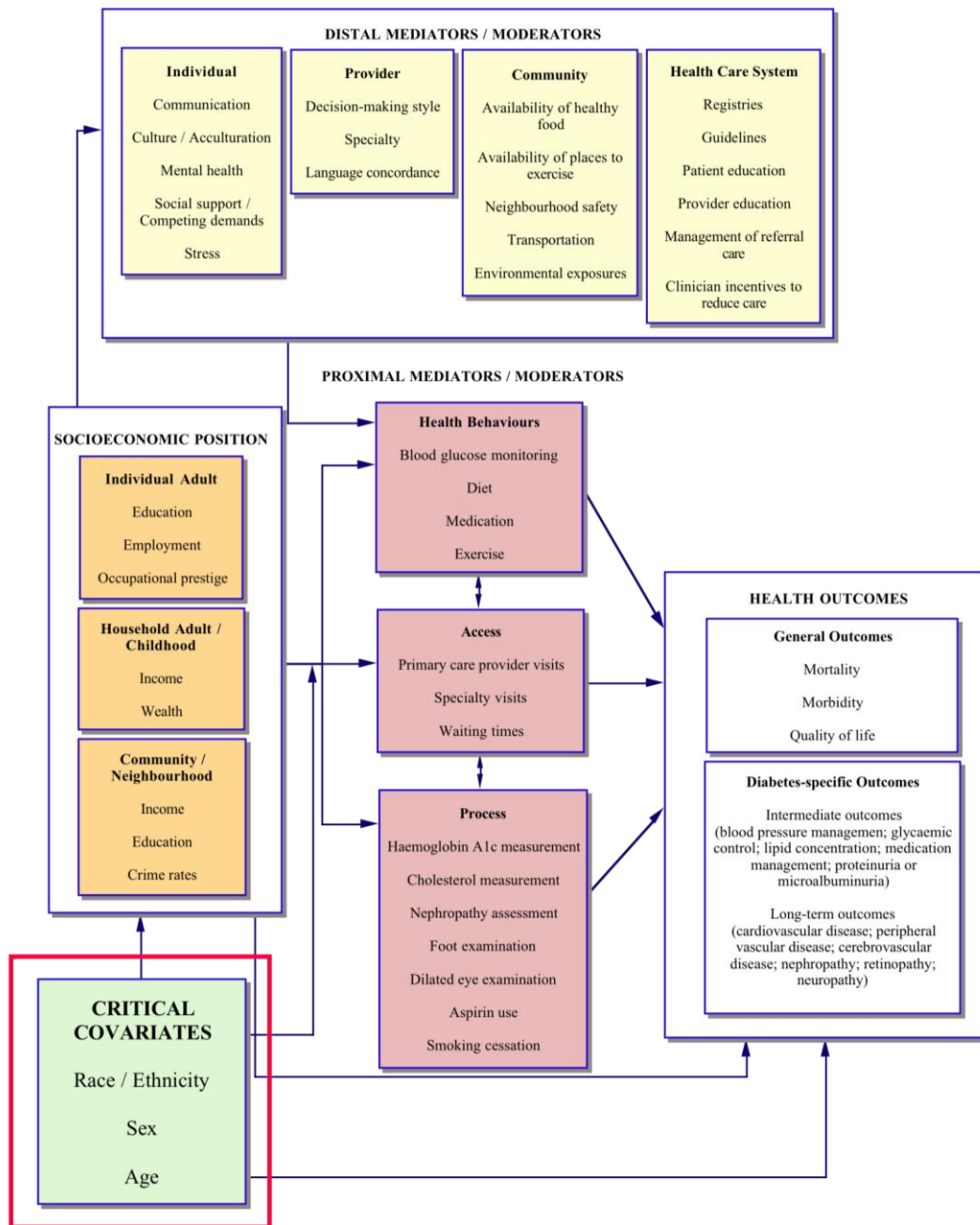


Figure 11.5: Conceptual framework for the link between SEP and health among persons with diabetes (critical covariates highlighted). Source: Brown and colleagues (2004).

The narratives of Indigenous participants revealed that their sense of well-being was strongly linked to that of their family and their community, and they perceived diabetes as having profoundly affected Aboriginal people and culture. Indigenous narratives were dominated by high levels of stress, primarily stemming from intergenerational worries and concerns, which impacted negatively on their sense of well-being, and, in turn, affected their ability to manage their disease. Indigenous participants identified competing family demands and responsibilities, and community concerns as sources of stress, leading to poor glycaemic control, while perceptions of

low control and lack of autonomy also featured strongly. These findings support other research carried out among urban Aboriginal communities (Thompson and Gifford 2000; Abbott *et al.* 2010), and need to be understood in the context of the deleterious effects of low control and lack of autonomy, leading to chronic stress (Marmot 2004). Consistent with data from Abbot and colleagues (2010), wanting to influence future generations was a motivator for leading healthier lifestyles; however, the unpredictability of household dynamics was found to impact on self-management, hindering efforts at implementing dietary changes.

Overall, the narratives of disease of Indigenous participants were linked to ‘narratives of dispossession and exclusion’ (Saggers and Gray 2007, 17), and were consistent with the social disadvantage experienced by Indigenous people in Australia (Thomson *et al.* 2010).

### **Sex/gender**

There was some evidence to suggest that *gender* – rather than *sex*, as identified by Brown and colleagues (2004) – may operate independently and moderate the influence on SES on diabetes health outcomes. In this study, women were generally responsible for meal preparation – which is consistent with data from the ABS on the distribution of household tasks (ABS 2006b) – and, thus, played a central role in implementing dietary changes to family meals to adopt healthier options. Furthermore, evidence from the interviews involving couples suggested that women may have higher levels of self-efficacy, which impact on their own self-management and that of their spouses.

### **Age**

The age of participants in this study ranged from the mid-twenties to mid-eighties. The narratives of younger participants yielded some evidence to suggest that the demands on time, energy, and finances of caring for young children were a source of added stress, and impacted negatively on self-management behaviours. Age of onset is a salient issue in diabetes, as persons who are diagnosed at a younger age are at higher risk of developing diabetes complications, and may be burdened by morbidity and quality of life issues early in life, while they are at the height of their productivity (Alberti *et al.* 2004).

## A modified framework for the pathways of diabetes disadvantage

By analysing the study results as they relate to the elements of the framework developed by Brown and colleagues (2004), I unveiled the ways in which the pathways of diabetes disadvantage operate in four metropolitan suburbs in Perth, Western Australia. Despite limitations relating to the source of the data, and participants' low awareness of the technical aspects of their care, I demonstrated the applicability of the model to qualitative inquiry, and in this section I present some amendments to the framework.

The modified framework highlights the main pathways of diabetes disadvantage based on the study results and is shown in Figure 11.6 (the amendments to the framework and the main pathways of disadvantage are highlighted in red, while the areas shaded in grey represent the elements and domains which could not be explored in this study). Under the *distal factors* element operating at individual level, I propose the addition of the domain of *family history* and the expansion of the *mental health* domain into a broader domain of *psychological well-being*, including mental health issues, self-efficacy and coping skills. In addition, I propose one amendment to the *proximal factors* element, expanding the *process* domain by incorporating *service quality* considerations. Finally, under the *critical covariates* element, I propose the expansion of the *sex* domain to incorporate issues of *gender*.

Participants' accounts revealed a strong relationship between *health outcomes* and *proximal factors*, in particular *health behaviours*, and highlighted the bi-directional nature of the influence. For most participants, poor health status exacerbated the deleterious effects of diabetes, placing restrictions on their ability to self-manage, which in turn resulted in poorer short-term and long-term outcomes.

Participants' experiences of self- and medical management (*proximal factors*) were embedded in their everyday circumstances (*distal factors*), and influenced by their limited resources (*SES*). More specifically, participants spoke of financial constraints (*SES*) limiting their ability to adopt a healthy diet and engage in physical activity (*health behaviours*), while their narratives also revealed barriers relating to cultural factors, social support, stress, and health literacy (*distal individual*). Participants reported cost (*SES, distal healthcare system*) as a barrier to *access* to non-medical

care, and their healthcare-seeking behaviours were also influenced by previous negative experiences, perceived need and lack of information (*individual distal*). Finally, participants' views on the quality of their care (*process*) were formed around personal characteristics, and were influenced by their limited health literacy (*SES* operating through *distal individual* characteristics).

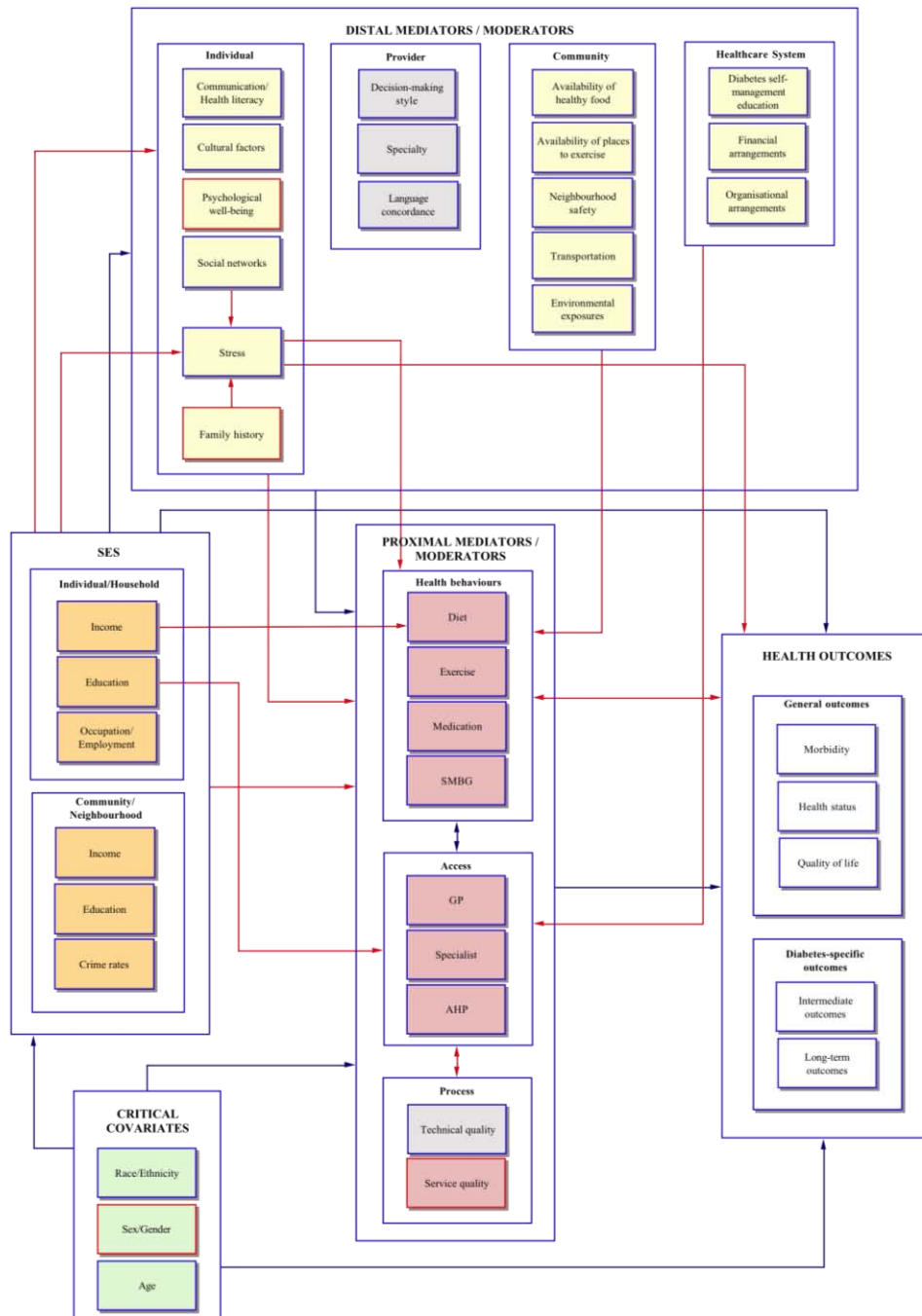


Figure 11.6: Modified framework for the link between SEP and diabetes health outcomes (main pathways highlighted). Source: Modified from Brown and colleagues (2004).

Complex and interweaving *distal factors* operating on different levels appeared to shape the structural and psychosocial environment in which participants experienced their disease, and their disease management and healthcare-seeking behaviour. Participants revealed that their attitudes towards disease and its complications were shaped by their *family history* of diabetes; they reported multiple external and diabetes-related *stressors* in their lives, which impacted negatively on their perceived quality of life and hindered self-management; and they revealed the dual role of social networks, enabling or hindering self-management behaviours. Some participants reported *neighbourhood safety* concerns as a barrier to exercise, and *transport* issues were also of concern. Finally, participants reported an uncoordinated model of care (*organisational arrangements*), with easy access to GPs, but inconsistent access to AHPs and diabetes self-management education.

In conclusion, participants revealed multilevel pathways through which SEP influenced their diabetes health outcomes, influencing specific health and health-care seeking behaviours (*proximal factors*), and shaping the circumstances and conditions in which their everyday experience of disease was embedded (*distal factors*).

## Chapter 12 – Conclusion

*Everybody has an equal right to inequality.*

(John Ralston Saul)

In this study, I explored the impact of socio-economic disadvantage on the experience of diabetes among a small sample of low income earners living in the metropolitan area of Perth. I grounded my approach within a social determinants of health perspective, and sought to understand participants' experiences and attitudes in the context of their daily lives.

I adopted a qualitative methodology to explore participants' understandings and experiences; however, I borrowed from a framework which has predominantly been tested through quantitative methods, once I was satisfied that it was congruent with the theoretical underpinnings of the study. By adopting this approach, I demonstrated the applicability of this framework to the exploration of the lay experience of diabetes, and hopefully contributed to further bridging the divide between quantitative and qualitative perspectives in public health.

This study demonstrated the multifaceted impact of socio-economic disadvantage on the experience of diabetes, illuminating specific pathways through which SES influences the attitudes and behaviours towards self- and medical management. Further, this study demonstrated the way in which poor diabetes management may exacerbate social disadvantage.

In the context of the increasing prevalence of diabetes in Australia, public health strategies should adopt a social determinants of health approach, and address the broad socio-structural factors shaping the vulnerability to diabetes and its consequences. Given the strong social patterning of diabetes, and its disproportionate burden on Indigenous Australians, it seems appropriate to frame tackling this challenging disease as an issue of equity and social justice, which will help bridge the health gap between Indigenous and non-Indigenous Australians.

While acknowledging the limitations of the study, I present some recommendations for further research, and some broad implications for policy and practice.

## ***Recommendations for further research***

This study explored the experience of diabetes among low income earners living in disadvantaged suburbs in the north metropolitan area of Perth. Limitations in the sample size preclude the generalisation of results to other disadvantaged suburbs and to the wider community. It is recommended that further research be conducted involving a larger sample and including other disadvantaged areas in Perth. It is also recommended that further research investigate the experiences of vulnerable CaLD groups within the metropolitan area to explore the common structural and social factors, as well as the cultural variation in their experience of diabetes.

Results from this study suggest that family history of diabetes strongly influences health and healthcare-seeking behaviours, shaping health beliefs and attitudes towards disease causation, progression and complications. It is recommended that further research on the influence of family history on disease management be conducted involving a larger sample to validate this finding and explore potential variations across SES groups.

Finally, results from this study showed limited awareness around foot care among participants. Given the association between disadvantage and diabetes complications, and, in particular, given the high levels of diabetes-related amputations among Indigenous people in Western Australia (Norman *et al.* 2010), further research exploring the attitudes and knowledge around foot care among vulnerable populations living with diabetes is warranted.

## ***Implications for policy and practice***

Results from this study suggest that socio-economic disadvantage places restrictions on the person's ability to adopt healthy behaviours around diabetes, highlighting the limitations of focusing on individual behaviours for the effective management of diabetes, and lending support to the view that, even when a behavioural focus is adopted, the social determinants of the risk factors which place an individual at higher risk of poor diabetes management need to be addressed (Yu and Raphael 2004). Because everyday context shapes diabetes management decisions (Raphael *et al.* 2003), self-management and medical management interventions for disadvantaged populations should address the underlying drivers of health and self-



management behaviours, and take into account the family, social, cultural and financial circumstances in which each individual experiences their disease.



## References

- Abbott, P., J. Davison, L. Moore, and R. Rubinstein. 2010. Barriers and enhancers to dietary behaviour change for Aboriginal people attending a diabetes cooking course. *Health Promotion Journal of Australia* 21 (1): 33-38.
- Aboriginal and Torres Strait Islander Social Justice Commissioner. 2005. *Social justice report 2005*. Sydney: Human Rights & Equal Opportunity Commission.
- ABS. 2006a. *Census of population and housing: Socio-economic indexes for areas (SEIFA)*. Cat no 2033.0.55.001. Canberra: Australian Bureau of Statistics.
- ABS. 2006b. *How Australians use their time 2006*. Cat. No. 4153.0. Canberra: Australian Bureau of Statistics.
- ABS. 2006c. *SEIFA postal areas*.  
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/2033.0.55.0012006> (accessed April 4, 2008).
- ABS. 2007a. *2006 Census QuickStats: 6061 (postal area)*. Canberra: Australian Bureau of Statistics.
- ABS. 2007b. *2006 Census QuickStats: Western Australia*. Canberra: Australian Bureau of Statistics.
- ABS. 2008a. *2006 Census community profile series: 6061 (postal area)*. Canberra: Australian Bureau of Statistics.
- ABS. 2008b. *2006 Census community profile series: Australia*. Canberra: Australian Bureau of Statistics.
- ABS. 2008c. *2006 Census community profile series: Western Australia*. Canberra: Australian Bureau of Statistics.
- ABS. 2008d. *Socio-economic indexes for areas (SEIFA): Technical paper*. Cat. no. 2039.0.55.001. Canberra: Australian Bureau of Statistics.
- ABS. 2009. *National health survey 2007-08: Summary of results*. Cat. no. 4363.0.55.001. Canberra: Australian Bureau of Statistics.
- Acheson, D. 1998. *Independent inquiry into inequalities in health report*. London: Stationary Office.
- AIHW. 2005a. *Chronic disease and associated risk factors*.  
<http://www.aihw.gov.au/cdarf/index.cfm> (accessed August 18, 2008).
- AIHW. 2005b. *National health priority areas*.  
<http://www.aihw.gov.au/nhpa/index.cfm> (accessed April 4, 2008).
- AIHW. 2008a. *Aboriginal and Torres Strait Islander health performance framework 2008 report*. Cat. no. IHW 22. Canberra: Australian Institute of Health and Welfare.

- AIHW. 2008b. *Diabetes: Australian facts 2008*. Diabetes series no. 8. Cat. no. CVD 40. Canberra: Australian Institute of Health and Welfare.
- AIHW. 2010. *Australia's health 2010*. Australia's health series no. 12. Cat. no. AUS 122. Canberra: Australian Institute of Health and Welfare.
- Alberti, G., P. Zimmet, J. Shaw, Z. Bloomgarden, F. Kaufman, and M. Silink. 2004. Type 2 diabetes in the young: The evolving epidemic. *Diabetes Care* 27 (7): 1798-1811.
- Anand, S. 2002. The concern for equity in health. *Journal of Epidemiology and Community Health* 56: 485-487.
- Anderson, R. J., K. E. Freedland, R. E. Clouse, and P. Lustman. 2001. The prevalence of co-morbid depression in adults with diabetes. *Diabetes Care* 24 (6): 1069-1078.
- Auld, G. W., M. A. Bock, C. J. Boushey, C. M. Bruhn, M. Cluskey, M. Edlefsen, D. L. Goldberg, S. L. Misner, B. H. Olson, M. Reicks, W. Changzheng, and S. Zaghoul. 2007. Development of a decision tree to determine appropriateness of NVivo in analyzing qualitative data sets. *Journal of Nutrition Education & Behaviour* 39: 37-47.
- Bachmann, M. O., J. Eachus, C. D. Hopper, G. D. Smith, C. Proppert, N. J. Pearson, S. Williams, D. Tallon, and S. Frankel. 2003. Socio-economic inequalities in diabetes complications, control, attitudes and health service use: A cross-sectional study. *Diabetic Medicine* 20: 921-929.
- Bambas, A., and J. A. Casas. 2003. Assessing equity in health: Conceptual criteria. In *Health and social justice: Politics, ideology, and inequity in the distribution of disease*, ed. R. Hofrichter, 321-334. San Francisco: Jossey Bass.
- Banks, J., M. Marmot, Z. Oldfield, and J. P. Smith. 2006. Disease and disadvantage in the United States and in England. *JAMA* 295 (17): 2037-2045.
- Banyard, V. L., and K. E. Miller. 1998. The powerful potential of qualitative research for community psychology. *American Journal of Community Psychology* 26 (4): 485-505.
- Barr, E. L. M., D. J. Magliano, P. Z. Zimmet, K. R. Polkinghorne, R. C. Atkins, D. W. Dunstan, S. G. Murray, and J. E. Shaw. 2006. *AusDiab 2005: The Australian diabetes, obesity and lifestyle study*. Melbourne: International Diabetes Institute.
- Baum, F. 2004. *The new public health*. 2nd ed. South Melbourne, Victoria: Oxford University Press.
- Beaglehole, R., and D. Yach. 2003. Globalisation and the prevention and control of non-communicable disease: The neglected chronic diseases of adults. *Lancet* 362: 903-908.

- Beauchamp, D. E. 2003. Public health as social justice. In *Health and social justice: Politics, ideology, and inequity in the distribution of disease*, ed. R. Hofrichter, 267-284. San Francisco: Jossey Bass.
- Berkman, L. F., and T. Glass. 2000. Social integration, social networks, social support, and health. In *Social epidemiology*, ed. L. Berkman and I. Kawachi, 137-173. New York: Oxford University Press.
- Berkman, L. F., and I. Kawachi. 2000. A historical framework for social epidemiology. In *Social epidemiology*, ed. L. F. Berkman and I. Kawachi, 3-12. New York: Oxford University Press.
- Bernard, P., R. Charafeddine, K. L. Frohlich, M. Daniel, Y. Kestens, and L. Potvin. 2007. Health inequalities and place: A theoretical conception of neighbourhood. *Social Science & Medicine* 65: 1839-52.
- Black, D., J. N. Morris, C. Smith, and P. Townsend. 1982. *Inequalities in health: The Black report*. Edited by P. Townsend and N. Davidson. Harmondsworth: Penguin Books Ltd.
- Blaxter, M. 1997. Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science & Medicine* 44 (6): 747-56.
- Bond Sutton, L., J. A. Erlen, J. M. Gland, and L. A. Siminoff. 2003. Recruiting vulnerable populations for research: Revisiting the ethical issues. *Journal of Professional Nursing* 19 (2): 106-112.
- Boutayeb, A. 2006. The double burden of communicable and non-communicable diseases in developing countries. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 100: 191-199.
- Brameld, K. J., and C. D. J. Holman. 2006. Demographic factors as predictors for hospital admission in patients with chronic disease. *Australian and New Zealand Journal of Public Health* 30 (6): 562-566.
- Braveman, P. 2006. Health disparities and health equity: Concepts and measurement. *Annual Review of Public Health* 27 (1): 167-194.
- Braveman, P., and S. Gruskin. 2003. Defining equity in health. *Journal of Epidemiology and Community Health* 57 (4): 254-258.
- Brimblecombe, J. K., and K. O'Dea. 2009. The role of energy cost in food choices for an Aboriginal population in northern Australia. *MJA* 190 (10): 549-551.
- Britten, N. 2006. Qualitative interviews. In *Qualitative research in health care*, ed. C. Pope and N. Mays, 12-20. Carlton, Victoria: Blackwell Publishing Ltd.
- Brod, M., J. H. Kongso, S. Lessard, and T. L. Christensen. 2009. Psychological insulin resistance: Patient beliefs and implications for diabetes management. *Quality of Life Research* 18: 23-32.
- Broom, D., and A. Whittaker. 2004. Controlling diabetes, controlling diabetics: Moral language in the management of diabetes type 2. *Social Science & Medicine* 58: 2371-2382.

- Brown, A. F., S. L. Ettner, J. Piette, M. Weinberger, E. Gregg, M. F. Shapiro, A. J. Karter, M. Safford, B. Waitzfelder, P. A. Prata, and G. L. Beckles. 2004. Socioeconomic position and health among persons with diabetes mellitus: A conceptual framework and review of the literature. *Epidemiologic Reviews* 26: 63-77.
- Bruce, D. G., W. A. Davis, C. A. Cull, and T. M. Davis. 2003. Diabetes education and knowledge in patients with type 2 diabetes from the community: The Fremantle Diabetes Study. *Journal of Diabetes and Its Complications* 17 (2): 82-89.
- Bruce, D. G., W. A. Davis, T. M. Starkstein, and T. M. E. Davis. 2005. A prospective study of depression and mortality in patients with type 2 diabetes: The Fremantle Diabetes Study. *Diabetologia* 48: 2535-2539.
- Bunton, R. 1998. Inequalities in late-modern health care. In *Health matters: A sociology of illness, prevention and care*, ed. A. Petersen and C. Waddel, 23-41. Sydney: Allen & Unwin Pty Ltd.
- Burgess, P., and J. Morrison. 2007. Country. In *Social determinants of Indigenous health*, ed. B. Carson, T. Dunbar, R. D. Chenhall and R. Bailie, 177-202. Singapore: Allen & Unwin.
- Burns, C. M., and A. D. Inglis. 2007. Measuring food access in Melbourne: Access to healthy and fast foods by car, bus and foot in an urban municipality in Melbourne. *Health & Place* 13 (4): 877-885.
- Caban, A., E. A. Walker, S. Sanchez, and M. S. Mera. 2008. "It feels like home when you eat rice and beans": Perspectives of urban Latinos living with diabetes. *Diabetes Spectrum* 21 (2): 120-27.
- Calma, T. 2009. *Close the gap campaign for Aboriginal and Torres Strait Islander health inequality by 2030: A community guide*. Canberra: Australian Human Rights Commission.
- Campos, P., A. Saguy, P. Ernsberger, E. Oliver, and G. Gaesser. 2006. The epidemiology of overweight and obesity: Public health crisis or moral panic? *International Journal of Epidemiology* 35: 55-60.
- Carter-Edwards, L., A. Skelly, C. Spence Cagle, and S. Appel. 2004. "They care but don't understand": Family support of African American women with type 2 diabetes. *The Diabetes Educator* 30 (3): 493-501.
- Carter, S. M., J. Ritchie, and P. Sainsbury. 2009. Doing good qualitative research in public health: Not as easy as it looks. *NSW Public Health Bulletin* 20 (7-8): 105-111.
- Charles, J., A. Ng, and G. Miller. 2006. Management of type 2 diabetes in Australian general practice. *Australian Family Physician* 35 (6): 378-379.
- Cheek, J. 2008. Healthism: A new conservatism? *Qualitative Health Research* 18 (7): 974-982.

- Chittleborough, C. R., F. E. Baum, A. W. Taylor, and J. E. Hiller. 2006. A life-course approach to measuring socioeconomic position in population health surveillance systems. *Journal of Epidemiology and Community Health* 60: 981-992.
- City of Stirling. 2002. *Mirraboooka Regional Centre improvement strategy*. <http://www.stirling.wa.gov.au/Mirraboooka+Regional+Centre/Mirraboooka+Regional+Centre.htm> (accessed August 12, 2009).
- City of Stirling. 2006. *Information directory 2006 to 2008*. City of Stirling.
- City of Stirling. 2008a. *Council*. <http://www.stirling.wa.gov.au> (accessed December 3, 2008).
- City of Stirling. 2008b. *Suburbs*. <http://www.stirling.wa.gov.au/home/council/Suburbs.htm> (accessed February 10, 2009).
- City of Stirling. 2009. *Integrated transport strategy [draft]*. <http://www.stirling.wa.gov.au> (accessed September 30, 2010).
- City of Stirling. 2010a. *Community profile*. <http://www.stirling.wa.gov.au/Home/Community/Community+Profile> (accessed October 22, 2010).
- City of Stirling. 2010b. *It'll get better in Mirraboooka*. <http://stirling.inmycommunity.com.au/news-and-views/local-news> (accessed September 28, 2010).
- City of Stirling. 2010c. *Local housing strategy 2010*. <http://www.stirling.wa.gov.au/NR/rdonlyres/AA3C66D3-B673-495C-9F9F-FE964590934D/0/LocalHousingStrategy2010.pdf> (accessed September 30, 2010).
- Coburn, D. 2004. Beyond the income inequality hypothesis: Class, neo-liberalism, and health inequalities. *Social Science and Medicine* 58: 41-56.
- Colagiuri, R., S. Colagiuri, D. Yach, and S. Prammings. 2006. The answer to diabetes prevention: Science, surgery, service delivery, or social policy? *American Journal of Public Health* 96 (9): 1562-1569.
- Colagiuri, R., S. Girgis, C. Eigenmann, M. Gomez, and R. Griffiths. 2009. *National evidence based guidelines for patient education in type 2 diabetes*. Canberra: Diabetes Australia and the NHMRC.
- Colagiuri, S., R. Colagiuri, B. Conway, D. Grainger, and P. Davey. 2003. *DiabCost Australia: Assessing the burden of type 2 diabetes in Australia*. Canberra: Diabetes Australia.
- Colagiuri, S., S. Dickinson, S. Girgis, and R. Colagiuri. 2009. *National evidence based guideline for blood glucose control in type 2 diabetes*. Canberra: Diabetes Australia and the NHMRC.

- Comino, E. J., O. Hermiz, M. F. Harris, and E. Harris. 2006. Evaluating access to and use of primary health care: Diabetes-related case study using the 2002/3 NSW Health Survey. *Australian Journal of Primary Health* 12 (3): 26-33.
- Cook, K., and K. Nunkoosing. 2008. Maintaining dignity and managing stigma in the interview encounter: The challenge of paid-for participation. *Qualitative Health Research* 18: 418-427.
- Cox, M., P. J. Boyle, P. G. Davey, Z. Feng, and A. D. Morris. 2007. Locality deprivation and type 2 diabetes incidence: A local test of relative inequalities. *Social Science & Medicine* 65: 1953-1964.
- Craig, M. E., G. Fernia, V. Broyda, M. Lloyd, and N. J. Howard. 2007. Type 2 diabetes in Indigenous and non-Indigenous children and adolescents in New South Wales. *Medical Journal of Australia* 186 (10): 497-499.
- Crawford, R. 1980. Healthism and the medicalization of everyday life. *International Journal of Health Services* 10 (3): 365-388.
- CSDH. 2008. *Closing the gap in a generation: Health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health*. Geneva: World Health Organization.
- Cunningham, J. 2010. Socio-economic gradients in self-reported diabetes for Indigenous and non-Indigenous Australians aged 18-64. *Australian and New Zealand Journal of Public Health* 34 (S1): S18-S24.
- DAGDC. 2009. *Overview of guideline development process and methods*. Canberra: Diabetes Australia and the NHMRC.
- Daly, J. 2009. Qualitative method and the curse of the illustrative quotation [Editorial]. *Australian and New Zealand Journal of Public Health* 33 (5): 405-406.
- Daniels, N. 1985. *Just health care. Studies in philosophy and health policy*. London: Cambridge University Press.
- Daniulaityte, R. 2004. Making sense of diabetes: Cultural models, gender and individual adjustment to type 2 diabetes in a Mexican community. *Social Science & Medicine* 59: 1899-1912.
- Davis, R. M., E. H. Wagner, and T. Groves. 1999. Managing chronic disease [editorial]. *British Medical Journal* 318: 1090-1091.
- Davis, T. M. E., D. McAullay, W. A. Davis, and D. G. Bruce. 2007. Characteristics and outcome of type 2 diabetes in urban Aboriginal people: The Fremantle Diabetes Study. *Internal Medicine Journal* 37 (1): 59-63.
- Davis, W. A., D. G. Bruce, and T. M. E. Davis. 2006. Is self-monitoring of blood glucose appropriate for all type 2 diabetic patients? *Diabetes Care* 29 (8): 1764-1770.



- Davis, W. A., D. G. Bruce, and T. M. E. Davis. 2007. Does self-monitoring of blood glucose improve outcome in type 2 diabetes? The Fremantle Diabetes Study. *Diabetologia* 50: 510-515.
- DCRG. 2006. *Diabetes Consumer Reference Group (WA): Terms of reference*. <http://diabeteswa.com.au/UserDir/Documents/DCRG/Diabetes%20Consumer%20Reference%20Group%20ToR.pdf> (accessed December 3, 2008).
- De Berardis, G., F. Pellegrini, M. Franciosi, M. Belfiglio, B. Di Nardo, S. Greenfield, S. H. Kaplan, M. C. E. Rossi, M. Sacco, G. Tognoni, M. Valentini, and A. Nicolucci. 2005. Are type 2 diabetic patients offered adequate foot care? The role of physician and patient characteristics. *Journal of Diabetes and Its Complications* 19: 319-327.
- de Ridder, D., R. Green, R. Kuijter, and H. van Middendorp. 2008. Psychological adjustment to chronic disease. *The Lancet* 372: 246-255.
- Delormier, T., K. L. Frohlich, and L. Potvin. 2009. Food and eating as social practice: Understanding eating patterns as social phenomena and implications for public health. *Sociology of Health & Illness* 31 (2): 215-228.
- Demakakos, P., J. Nazroo, E. Breeze, and M. Marmot. 2008. Socioeconomic status and health: The role of subjective social status. *Social Science & Medicine* 67 (2): 330-340.
- Derbarl Yerrigan Health Service Inc. 2009. *Derbarl Yerrigan Health Service Inc*. <http://www.derbarlyerrigan.com.au> (accessed January 11, 2011).
- Diabetes Australia. 2010. *Diabetes management in general practice: Guidelines for type 2 diabetes 2010/11*. 16th ed. Gorokan, New South Wales: Diabetes Australia.
- Diabetes WA. 2008. *Annual review 2008*. <http://diabeteswa.com.au/UserDir/Documents/2008%20Annual%20Review%20FINAL.pdf> (accessed December 3, 2008).
- Dietitians Association of Australia. 2006. *Evidence based practice guidelines for the nutritional management of type 2 diabetes mellitus for adults*. <http://www.daa.asn.au> (accessed September, 2010).
- Dovey-Pearce, G., Y. Doherty, and C. May. 2007. The influence of diabetes upon adolescent and young adult development: A qualitative study. *British Journal of Health Psychology* 12 (1): 75-91.
- Draper, G., G. Turrel, and B. Oldenburgh. 2005. *Health inequalities in Australia: Mortality*. Health inequalities monitoring series no. 1. Cat. no. PHE 55. Canberra: Queensland University of Technology and AIHW.
- Dunstan, D., P. Zimmet, T. Welborn, R. Sicree, T. Armstrong, R. Atkins, A. Cameron, J. Shaw, and S. Chadban. 2001. *The Australian diabetes, obesity and lifestyle study (AusDiab)*. Melbourne: International Diabetes Institute.

- Dussart, F. 2009. Diet, diabetes and relatedness in a central Australian Aboriginal settlement: Some qualitative recommendations to facilitate the creating of culturally sensitive health promotion initiatives. *Health Promotion Journal of Australia* 20 (3): 202-207.
- Eckersley, R. 2004. The social origins of health. In *Well & good: How we feel & why it matters*, 59-76. Melbourne: The Text Publishing Company.
- Egede, L. E., and M. E. Poston. 2004. Racial/ethnic differences in leisure-time physical activity level among individuals with diabetes. *Diabetes Care* 27 (10): 2493-2494.
- Eigenmann, C., and R. Colagiuri. 2007. *Outcomes and indicators for diabetes education: A national consensus position*. Canberra: Diabetes Australia.
- El Achhab, Y., C. Nejjari, M. Chikri, and B. Lyoussi. 2008. Disease-specific health-related quality of life instruments among adults diabetic: A systematic review. *Diabetes Research and Clinical Practice* 80: 171-184.
- Ember, C. R., M. Ember, and P. N. Peregrine. 2005. *Anthropology*. 11th ed. New Jersey: Pearson Education, Inc.
- FaHCSIA. 2009. *Closing the gap on Indigenous disadvantage: The challenge for Australia*. Canberra: Commonwealth of Australia.
- Fernandez, J. A., M. R. J. Walsh, M. G. Maller, and W. Wrapson. 2008. *Crimes reported to Police, Western Australia 2006*. Crime Research Centre, University of Western Australia.
- Ferzacca, S. 2000. "Actually, I don't feel that bad": Managing diabetes and the clinical encounter. *Medical Anthropology Quarterly* 14 (1): 28-50.
- Finucane, M. M., G. A. Stevens, M. J. Cowan, G. Danaei, J. K. Lin, C. J. Paciorek, G. M. Singh, H. R. Gutierrez, Y. Lu, A. N. Bahalim, F. Farzadfar, L. M. Riley, and M. Ezzati. 2011. National, regional, and global trends in body-mass index since 1980: Systematic analysis of health examination surveys and epidemiological studies with 960 country-years and 9.1 million participants. *The Lancet* 377 (9765): 557-567.
- Fossey, E., C. Harvey, F. McDermott, and L. Davidson. 2002. Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry* 36: 717-732.
- Fritschi, C., and L. Quinn. 2010. Fatigue in patients with diabetes: A review. *Journal of Psychosomatic Research* 69: 33-41.
- Fry, C., and R. Dwyer. 2001. For love or money? An exploratory study of why injecting drug users participate in research. *Addiction* 96: 1319-1325.
- Fry, C. L., A. Ritter, S. Baldwin, K. J. Bowen, P. Gardiner, T. Holt, R. Jenkinson, and J. Johnston. 2005. Paying research participants: A study of current practices in Australia. *Journal of Medical Ethics* 31: 542-547.

- Galvin, R. 2002. Disturbing notions of chronic illness and individual responsibility: Towards a genealogy of morals. *Health* 6 (2): 107-137.
- Garcia-Horta, J. B., and M. T. Guerra-Ramos. 2009. The use of CAQDAS in educational research: Some advantages, limitations and potential risks. *International Journal of Research & Method in Education* 32 (2): 151-165.
- Garcia de Alba Garcia, J., A. Salcedo Rocha, I. Lopez, R. Baer, W. Dressler, and S. Weller. 2007. "Diabetes is my companion": Lifestyle and self-management among good and poor control Mexican diabetic patients. *Social Science & Medicine* 64 (2223-2235):
- Gary, T. L., M. M. Safford, R. B. Gerzoff, S. L. Ettner, A. J. Karter, G. L. Beckles, and A. F. Brown. 2008. Perception of neighbourhood problems, health behaviours, and diabetes outcomes among adults with diabetes in managed care. *Diabetes Care* 31 (2): 273-278.
- Gask, L., E. Ludman, and J. Schaefer. 2006. Qualitative study of an intervention for depression among patients with diabetes: How can we optimize patient-professional interaction? *Chronic Illness* 2 (3): 231-242.
- Gebel, K., A. Bauman, and M. Petticrew. 2007. The physical environment and physical activity: A critical appraisal of review articles. *American Journal of Preventive Medicine* 32 (5): 361-369.
- General Assembly of the United Nations. 2007. Resolution 61/225. World Diabetes Day. United Nations.
- Giles-Corti, B., and R. J. Donovan. 2002. The relative influence of individual, social and physical environment determinants of physical activity. *Social Science & Medicine* 54: 1793-1812.
- Glasgow, R. E., E. H. Wagner, R. M. Kaplan, F. Vinicor, L. Smith, and J. Norman. 1999. If diabetes is a public health problem, why not treat it as one? A population-based approach to chronic illness. *Annals of Behavioral Medicine* 21 (2): 159-170.
- Glover, J., D. Hetzel, and S. Tennant. 2004. The socioeconomic gradient and chronic illness and associated risk factors in Australia. *Australia and New Zealand Health Policy* 1: 8.
- Google Map. 2010. *Google Map Australia*. <http://maps.google.com.au> (accessed October 25, 2010).
- Goyder, E. C., J. L. Botha, and P. G. McNally. 2000. Inequalities in access to diabetes care: Evidence from a historical cohort study. *Quality in Health Care* 9: 85-89.
- Green, J., K. Willis, E. Hughes, R. Small, N. Welch, L. Gibbs, and J. Daly. 2007. Generating best evidence from qualitative research: The role of data analysis. *Australian and New Zealand Journal of Public Health* 31 (6): 545-550.

- Gregory, S. 2005. Living with chronic illness in the family setting. *Sociology of Health & Illness* 27 (3): 372-392.
- Grisby, A. B., R. J. Anderson, K. E. Freedland, R. E. Clouse, and P. J. Lustman. 2002. Prevalence of anxiety in adults with diabetes: A systematic review. *Journal of Psychosomatic Research* 53 (6): 1053-1060.
- Guillemin, M., and L. Gillam. 2004. Ethics, reflexivity, and 'ethically important moments' in research. *Qualitative Inquiry* 10: 261-280.
- Guy, C. M., and G. David. 2004. Measuring physical access to 'healthy foods' in areas of social deprivation: A case study in Cardiff. *International Journal of Consumer Studies* 28 (3): 222-234.
- Handley, J., S. Pullon, and H. Gifford. 2010. Living with type 2 diabetes: "Putting the person in the pilot's seat". *Australian Journal of Advanced Nursing* 27 (3): 12-19.
- Harrison, M., A. Lee, M. Findlay, R. Nicholls, D. Leonard, and C. Martin. 2010. The increasing cost of healthy food. *Australian and New Zealand Journal of Public Health* 34 (2): 179-186.
- Heart Foundation. 2010. *Guidelines and Patient Resources*. [http://www.heartfoundation.org.au/Professional\\_Information/General\\_Practice](http://www.heartfoundation.org.au/Professional_Information/General_Practice) (accessed September, 2010).
- Hernandez, C. A. 1995. The experience of living with insulin-dependent diabetes: Lessons for the diabetes educator. *The Diabetes Educator* 21 (1): 33-37.
- Heron, J. 1996. Quality as the primacy of the practical. *Qualitative Inquiry* 2: 41-56.
- Hewitt, J. 2007. Ethical components of researcher researched relationships in qualitative interviewing. *Qualitative Health Research* 17: 1149-1159.
- Heymann, S. J. 2000. Health and social policy. In *Social epidemiology*, ed. L. Berkman and I. Kawachi, 368-382. New York: Oxford University Press.
- Hofrichter, R. 2003. The politics of health inequalities: Contested terrain. In *Health and social justice: Politics, ideology, and inequity in the distribution of disease*, ed. R. Hofrichter, 1-56. San Francisco: Jossey-Bass.
- Horowitz, C. R., K. A. Colson, P. L. Hebert, and K. Lancaster. 2004. Barriers to buying healthy foods for people with diabetes: Evidence of environmental disparities. *American Journal of Public Health* 94 (9): 1549-1554.
- Horton, R. 2005. The neglected epidemic of chronic disease. *The Lancet* 366 (9496): 1514.
- IDF. 2009. *Complications of diabetes*. <http://www.idf.org/complications-diabetes> (accessed June 11, 2010).
- IDF Clinical Guidelines Task Force. 2005. *Global guidelines for type 2 diabetes*. Brussels: International Diabetes Federation.

- Infante, F. A., J. G. Proudfoot, G. Powell Davies, T. K. Bubner, C. H. Holton, J. J. Beilby, and M. F. Harris. 2004. How people with chronic illnesses view their care in general practice: A qualitative study. *MJA* 181 (2): 70-73.
- Inglis, V., K. Ball, and D. Crawford. 2005. Why do women of low socioeconomic status have poorer dietary behaviours than women of higher socioeconomic status? A qualitative exploration. *Appetite* 45: 334-343.
- International Society for Equity in Health. 2010. *International Society for Equity in Health*. <http://www.iseqh.org> (accessed March 15, 2011).
- Jack, S. M. 2006. Utility of qualitative research findings in evidence-based public health practice. *Public Health Nursing* 23 (3): 277-283.
- Jackman, M. R., and R. W. Jackman. 1973. Interpretation of the relation between objective and subjective social status. *American Sociological Review* 38 (5): 569-582.
- Jamrozik, K. 2010. Health literacy, victim blaming and the mission of public health [editorial]. *Australian and New Zealand Journal of Public Health* 34 (3): 227.
- Jeon, Y.-H., B. Essue, S. Jan, R. Wells, and J. A. Whitworth. 2009. Economic hardship associated with managing chronic illness: A qualitative inquiry. *BMC Health Services Research* 9: 182.
- Jordan, J. E., R. Buchbinder, and R. H. Osborne. 2010. Conceptualising health literacy from the patient perspective. *Patient Education and Counseling* 79: 36-42.
- Kavanagh, A. M., J. L. Goller, T. King, D. Jolley, D. Crawford, and G. Turrell. 2005. Urban area disadvantage and physical activity: A multilevel study in Melbourne, Australia. *Journal of Epidemiology and Community Health* 59: 934-940.
- Kawachi, I., N. Daniels, and D. E. Robinson. 2005. Health disparities by race and class: Why both matter. *Health Affairs* 24 (2): 343-352.
- Kawachi, I., S. V. Subramanian, and N. Almeida-Filho. 2002. A glossary for health inequalities. *Journal of Epidemiology and Community Health* 56 (9): 647-652.
- King, T., A. m. Kavanagh, D. Jolley, G. Turrell, and D. Crawford. 2006. Weight and place: A multilevel cross-sectional survey of area-level social disadvantage and overweight/obesity in Australia. *International Journal of Obesity* 30: 281-187.
- Kington, R. S., and J. P. Smith. 1997. Socioeconomic status and racial and ethnic differences in functional status associated with chronic diseases. *American Journal of Public Health* 87 (5): 805-810.
- Kitzinger, J. 2006. Focus groups. In *Qualitative research in health care*, ed. C. Pope and N. Mays, 21-31. Carlton, Victoria: Blackwell Publishing Ltd.

- Kokanovic, R., and L. Manderson. 2006. Social support and self-management of type 2 diabetes among immigrant Australian women. *Chronic Illness* 2: 291-301.
- Kokanovic, R., and L. Manderson. 2007. Exploring doctor-patient communication in immigrant Australians with type 2 diabetes: A qualitative study. *Journal of General Internal Medicine* 22: 459-463.
- Korda, R. J., E. Banks, M. S. Clements, and A. F. Young. 2009. Is inequity undermining Australia's 'universal' health care system? Socio-economic inequalities in the use of specialist medical and non-medical ambulatory health care. *Australian and New Zealand Journal of Public Health* 33 (5): 458-465.
- Korda, R. J., J. R. G. Butler, M. S. Clements, and S. J. Kunitz. 2007. Differential impacts of health care in Australia: Trend analysis of socioeconomic inequalities in avoidable mortality. *International Journal of Epidemiology* 36: 157-165.
- Kumari, M., J. Head, and M. Marmot. 2004. Prospective study of social and other risk factors for incidence of type 2 diabetes in the Whitehall II Study. *Archives of Internal Medicine* 164 (17): 1873-1880.
- Larrañaga, I., J. M. Arteagoitia, J. L. Rodriguez, F. Gonzalez, S. Esnaola, and J. A. Pinies. 2005. Socio-economic inequalities in the prevalence of type 2 diabetes, cardiovascular risk factors and chronic diabetic complications in the Basque Country, Spain. *Diabetic Medicine* 22 (8): 1047-1053.
- Lawton, J., N. Ahmad, L. Hanna, M. Douglas, and N. Hallowell. 2006a. Diabetes service provision: A qualitative study of the experiences and views of Pakistani and Indian patients with type 2 diabetes. *Diabetic Medicine* 23 (1003-1007):
- Lawton, J., N. Ahmad, L. Hanna, M. Douglas, and N. Hallowell. 2006b. "I can't do any serious exercise": Barriers to physical activity amongst people of Pakistani and Indian origin with type 2 diabetes. *Health Education Research* 21 (1): 43-54.
- Lawton, J., N. Ahmad, E. Peel, and N. Hallowell. 2007. Contextualising accounts of illness: Notions of responsibility and blame in white and South Asian respondents' accounts of diabetes causation. *Sociology of Health & Illness* 29 (6): 891-906.
- Lee, D. Y. L. 2007. The development and evaluation of written medicines information for type 2 diabetes. *Health Education Research* 22 (6): 918-930.
- Lin, E. H. B., W. Katon, M. Von Korff, C. Rutter, G. E. Simon, M. Oliver, P. Ciechanowski, E. J. Ludman, T. Bush, and B. Young. 2004. Relationship of depression and diabetes self-care, medication adherence, and preventive care. *Diabetes Care* 27 (9): 2154-2160.
- Lindbladh, E., C. H. Lyttkens, B. S. Hanson, and P.-O. Ostergren. 1998. Equity is out of fashion? An essay on autonomy and health policy in the individualized society. *Social Science & Medicine* 46 (8): 1017-1025.

- Lindström, M. 2008. Social capital and health-related behaviours. In *Social capital and health*, ed. I. Kawachi, S. Subramanian and D. Kim, 215-38. Springer: New York.
- Lishman, M. 2003. Chronic disease self-management in patients living in lower socio-economic areas: A WA perspective. *Australian Journal of Primary Health* 9 (2 & 3): 150-154.
- Litva, A., and J. Eyles. 1994. Health or healthy: Why people are not sick in a southern Ontarian town. *Social Science & Medicine* 39 (8): 1083-1091.
- Loader, B. D., S. Muncer, R. Burrows, N. Pleace, and S. Nettleton. 2002. Medicine on the line? Computer-mediated social support and advice for people with diabetes. *International Journal of Social Welfare* 11: 53-65.
- Lomas, J., T. Culyier, C. McCutcheon, L. McAuley, and S. Law. 2005. *Conceptualizing and combining evidence for health system guidance*. Ottawa: Canadian Health Services Research Foundation.
- Loos, M., and S. Kelly. 2006. Social well-being of siblings living with a child with diabetes: A qualitative study. *Social Work in Health Care* 43 (4): 53-69.
- Loxley, W., J. W. Toumbourou, T. Stockwell, B. Haines, K. Scott, C. Godfrey, E. Waters, G. Patton, R. Fordham, D. Gray, J. Marshall, D. Ryder, S. Siggers, L. Sanci, and J. Williams. 2004. *The prevention of substance use, risk and harm in Australia: A review of the evidence*. Canberra: Commonwealth of Australia.
- Lupton, D. 2000. The heart of the meal: Food preferences and habits among rural Australian couples. *Sociology of Health & Illness* 22 (1): 94-109.
- Lustman, P. J., and R. E. Clouse. 2005. Depression in diabetic patients: The relationship between mood and glycaemic control. *Journal of Diabetes and its Complications* 19 (2): 113-122.
- Lynch, J. 2000. Social epidemiology: Some observations about the past, present and future. *Australasian Epidemiologist* 7 (3): 7-15.
- Lynch, J. W., G. A. Kaplan, and J. T. Salonen. 1997. Why do poor people behave poorly? Variation in adult health behaviours and psychosocial characteristics by stages of the socioeconomic lifecourse. *Social Science & Medicine* 44 (6): 809-819.
- Lynch, J. W., G. D. Smith, G. A. Kaplan, and J. S. House. 2000. Income inequality and mortality: Importance to health of individual income, psychosocial environment, or material conditions. *British Medical Journal* 320: 1200-1203.
- Lynch, J. W., G. D. Smith, G. A. Kaplan, and J. S. House. 2003. Income inequality and mortality: Importance to health of individual income, psychosocial environment, or material conditions. In *Health and social justice: Politics,*

- ideology, and inequity in the distribution of disease*, ed. R. Hofrichter, 217-227. San Francisco: Jossey-Bass.
- Macinko, J., and B. Starfield. 2002. Annotated bibliography on equity in health, 1980-2001. *International Journal for Equity in Health* 1 (1): 1-20.
- Mackenbach, J., V. Bos, O. Andersen, M. Cardano, G. Costa, S. Harding, A. Reid, Ö. Heneström, T. Valkonen, and A. Kunst. 2003. Widening socioeconomic inequalities in mortality in six Western European countries. *International Journal of Epidemiology* 32: 830-837.
- Mackenbach, J., I. Stirbu, A.-J. Roskam, M. Schaap, G. Menvielle, M. Leinsalu, and A. Kunst. 2008. Socioeconomic inequalities in health in 22 European countries. *New England Journal of Medicine* 358 (23): 2468-2481.
- Magnusson, R. 2009. Personal responsibility, obesity prevention and front-of-pack food labelling. *Public Health Law* 6 (3): 12-17.
- Manderson, L., and R. Kokanovic. 2009. "Worried all the time": Distress and the circumstances of everyday life among immigrant Australians with type 2 diabetes. *Chronic Illness* 5: 21-32.
- Marmot, M. 2004. *The status syndrome: How social standing affects our health and longevity*. New York: Times Books.
- Marmot, M., and R. G. Wilkinson. 2001. Psychosocial and material pathways in the relation between income and health: A response to Lynch et al. *British Medical Journal* 322: 1233-1236.
- Massat, C. R., and M. Lundy. 1997. Empowering research participants. *Affilia* 12: 33-56.
- Mayer, D., and A. Rosenfeld. 2006. Symptom interpretation in women with diabetes and myocardial infarction: A qualitative study. *The Diabetes Educator* 32 (6): 918-924.
- Mays, N., and C. Pope. 1995. Rigour and qualitative research. *British Medical Journal* 311: 109-112.
- Mays, N., and C. Pope. 2000. Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal* 320: 50-52.
- McKinlay, J., and L. Marceau. 2000. US public health and the 21st century: Diabetes mellitus. *Lancet* 356: 757-761.
- McLellan, A. T. 2002. Have we evaluated addiction treatment correctly? Implications from a chronic care perspective. *Addiction* 97: 249-252.
- McNeill, L. H., M. W. Kreuter, and S. V. Subramanian. 2006. Social environment and physical activity: A review of concepts and evidence. *Social Science & Medicine* 63 (4): 1011-1022.
- Mercado-Martinez, F. J., and I. M. Ramos-Herrera. 2002. Diabetes: The layperson's theories of causality. *Qualitative Health Research* 12 (6): 792-806.



- Michailakis, D., and W. Schirmer. 2010. Agents of their own health? How the Swedish welfare state introduces expectations of individual responsibility. *Sociology of Health & Illness* 32 (6): 930-947.
- Miller, D. 1976. *Social justice*. Oxford: Clarendon Press.
- Minichiello, V., R. Aroni, and T. Hays. 2008. *In-depth interviewing*. 3rd ed. Frenchs Forest, Sydney: Pearson Education Australia.
- Morland, K., and S. Filomena. 2008. The utilization of local food environments by urban seniors. *Preventive Medicine* 47: 289-293.
- Morse, J. M. 2005. The paid/unpaid work of participants. *Qualitative Health Research* 15: 727-8.
- Morse, J. M. 2007. What is the domain of qualitative health research? *Qualitative Health Research* 17: 715-717.
- Nagelkerk, J., K. Reick, and L. Meengs. 2006. Perceived barriers and effective strategies to diabetes self-management. *Journal of Advanced Nursing* 54 (2): 151-158.
- Nair, K. M., L. R. Dolovich, D. K. Ciliska, and H. N. Lee. 2005. The perception of continuity of care from the perspective of patients with diabetes. *Family Medicine* 37 (2): 118-124.
- Naqshbandi, M., S. B. Harris, J. G. Esler, and F. Antwi-Nsiah. 2008. Global complication rates of type 2 diabetes in Indigenous peoples: A comprehensive review. *Diabetes Research and Clinical Practice* 82: 1-17.
- National Health Priority Action Council. 2006. *National Chronic Disease Strategy*. Canberra: Australian Government Department of Health and Ageing.
- Navarro, V., and L. Shi. 2001. The political context of social inequalities and health. *Social Science and Medicine* 52 (3): 481-491.
- NHMRC. 1999. *National physical activity guidelines for adults*. Canberra: Commonwealth of Australia.
- NHMRC. 2003a. *Dietary guidelines for Australian adults*. Canberra: Commonwealth of Australia.
- NHMRC. 2003b. *Values and ethics: Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research*. Canberra: Commonwealth of Australia.
- NHMRC. 2007. *National statement on ethical conduct in human research*. Canberra: Commonwealth of Australia.
- NHMRC. 2009. *Australian guidelines to reduce health risks from drinking alcohol*. Canberra: Commonwealth of Australia.

- Norman, P. E., D. E. Schoen, J. M. Gurr, and M. L. Kolybaba. 2010. High rates of amputation among Indigenous people in Western Australia. *Medical Journal of Australia* 192 (7): 421.
- O'Dea, K. 1984. Marked improvement in carbohydrate and lipid metabolism in diabetic Australian aborigines after temporary reversion to tradition lifestyle. *Diabetes* 33 (6): 596-603.
- O'Leary, Z. 2005. *Researching real-world problems: A guide to methods of inquiry*. London: Sage Publications Inc.
- Oakley, A. 2004. Qualitative research and scientific inquiry. *Australian and New Zealand Journal of Public Health* 28 (2): 106-108.
- OECD. 2007. *Health at a glance 2007: OECD indicators*. <http://www.oecd.org/health/healthataglance> (accessed August 27, 2008).
- OECD. 2009. *Health at a glance: OECD indicators*. Paris: OECD Publishing.
- OECD. 2010. *OECD Health data 2010: Statistics and indicators*. <http://www.oecd.org/health/healthdata> (accessed January 3, 2011).
- Office of the High Commissioner for Human Rights. 2011. *Universal Declaration of Human Rights*. <http://www.ohchr.org/en/udhr/pages/introduction.aspx> (accessed March 15, 2011).
- Oliver, N., D. Perkins, L. Hare, and K. Larsen. 2007. 'Stories from the past, the reality of the present, taking control of the future': Lifestyle changes among Pukapuka people in the Illawarra. *Health Promotion Journal of Australia* 18 (2): 105-108.
- Olshansky, S. J., D. J. Passaro, and R. C. Hershov. 2005. A potential decline in life expectancy in the United States in the 21st century. *New England Journal of Medicine* 352: 1138-1145.
- Omran, A. R. 1971. The epidemiological transition: A theory of the epidemiology of population change. *The Milbank Memorial Fund Quarterly* 49 (4): 509-538.
- Östlin, P., P. Braveman, J. N. Dachs, and G. Dahlgren. 2005. Priorities for research to take forward the health equity policy agenda. *Bulleting of the World Health Organization* 83 (12): 948-953.
- Page, A., M. Tobias, J. Glover, C. Wright, D. Hetzel, and E. Fisher. 2006. *Australian and New Zealand Atlas of Avoidable Mortality*. Adelaide: PHIDU, University of Adelaide.
- Pappas, G., A. A. Hyder, and M. Akhter. 2003. Globalization: Toward a new framework for public health. *Social Theory & Health* 1: 91-107.
- Parry, O., E. Peel, M. Douglas, and J. Lawton. 2004. Patients in waiting: A qualitative study of type 2 diabetes patients' perceptions of diagnosis. *Family Practice* 21 (2): 131-136.

- Parry, O., E. Peel, M. Douglas, and J. Lawton. 2006. Issues of cause and control in patient accounts of type 2 diabetes. *Health Education Research* 21 (1): 97-107.
- Patton, M. Q. 2002. *Qualitative research & evaluation methods*. 3rd ed. Thousand Oaks, California: Sage Publications Inc.
- Pearce, J., K. Witten, and P. Bartie. 2006. Neighbourhoods and health: A GIS approach to measuring community resource accessibility. *Journal of Epidemiology and Community Health* 60: 389-395.
- Peel, E., M. Douglas, and J. Lawton. 2007. Self monitoring of blood glucose in type 2 diabetes: Longitudinal qualitative study of patients' perspectives. *BMJ* 335 (7618): 493-498.
- Peyrot, M., R. R. Rubin, T. Lauritzen, S. E. Skovlund, F. J. Snoek, D. R. Matthews, R. Landgraf, and L. Kleinebreil. 2005. Resistance to insulin therapy among patients and providers. *Diabetes Care* 28 (11): 2673-2679.
- Peyrot, M., R. R. Rubin, T. Lauritzen, F. J. Snoek, D. R. Matthews, and S. E. Skovlund. 2005. Psychosocial problems and barriers to improved diabetes management: Results of the cross-national Diabetes Attitudes, Wishes and Needs (DAWN) study. *Diabetic Medicine* 22: 1379-1385.
- PHIAC. 2008. *Private Health Insurance Administration Council annual report 2007-08*. Canberra: PHIAC.
- Pooley, C. G., C. Gerrard, S. Hollis, S. Morton, and J. Astbury. 2001. "Oh it's a wonderful practice... you can talk to them": A qualitative study of patients' and health professionals' views on the management of type 2 diabetes. *Health & Social Care in the Community* 9 (5): 318-326.
- Popay, J., S. Bennet, C. Thomas, G. Williams, A. Gatrell, and L. Bostock. 2003. Beyond 'beer, fags, egg and chips'? Exploring lay understandings of social inequalities in health. *Sociology of Health & Illness* 25 (1): 1-23.
- Pope, C., and N. Mays. 2006. Qualitative methods in health research. In *Qualitative research in health care*, ed. C. Pope and N. Mays, 1-11. Carlton, Victoria: Blackwell Publishing Ltd.
- Pope, C., S. Ziebland, and N. Mays. 2006. Analysing qualitative data. In *Qualitative research in health care*, ed. C. Pope and N. Mays, 63-81. Carlton, Victoria: Blackwell Publishing Ltd.
- Prah Ruger, J. 2004. Ethics of the social determinants of health. *Lancet* 364: 1092-1097.
- QSR International. 2007. *NVivo 8*.  
[http://www.qsrinternational.com/products\\_nvivo.aspx](http://www.qsrinternational.com/products_nvivo.aspx) (accessed April 7, 2008).
- Raphael, D., S. Anstice, K. Raine, K. R. McGannon, S. Kamil Rizvi, and V. Yu. 2003. The social determinants of the incidence and management of type 2

- diabetes mellitus: Are we prepared to rethink our questions and redirect our research activities? *Leadership in Health Services* 16 (3): 10-20.
- Rawls, J. 1971. *A theory of justice*. Cambridge, Massachusetts: Harvard University Press.
- Rees Jones, I. 2003. Power, present and past: For a historical sociology of health and illness. *Social Theory & Health* 1: 130-148.
- Richards, L. 1999. Data alive! The thinking behind NVivo. *Qualitative Health Research* 9 (3): 412-428.
- Ritchie, J., L. Spencer, and W. O'Connor. 2003. Carrying out qualitative analysis. In *Qualitative research practice: A guide for social scientists and researchers*, ed. J. Ritchie and J. Lewis, 219-262. London: SAGE.
- Robbins, J. M., V. Vaccarino, and S. V. Kasl. 2001. Socioeconomic status and type 2 diabetes in African American and non-Hispanic white women and men: Evidence from the Third National Health and Nutrition Examination Survey. *American Journal of Public Health* 91 (1): 76-83.
- Robertson, S. P. 2008. The qualitative research process as a journey. *Qualitative Research Journal* 8 (2): 81-90.
- Rose, G. 1992. *The strategy of preventive medicine*. New York: Oxford University Press.
- Rose, V. 2005. Socioeconomic barriers to diabetes self-care: Development of a factor analytic scale. *Australasian Epidemiologist* 12 (2): 15-17.
- Rose, V., M. Harris, and M. T. Ho. 2004. GP's views on how low socioeconomic position affects diabetes management: An exploratory study. *Australian Journal of Primary Health* 10 (3): 120-123.
- Roy, S. C. 2008. "Taking charge of your health": Discourses of responsibility in English-Canadian women's magazines. *Sociology of Health & Illness* 30 (3): 463-477.
- Rozario, P. A., and D. Derienzis. 2009. "So forget how old I am!" Examining age identities in the face of chronic conditions. *Sociology of Health & Illness* 31 (4): 540-553.
- Rubin, R. R. 2001. Facilitating self-care in people with diabetes. *Diabetes Spectrum* 14 (2): 55-57.
- Rubin, R. R., M. Peyrot, and L. M. Siminerio. 2006. Health care and patient-reported outcomes: Results of the cross-national Diabetes Attitudes, Wishes and Needs (DAWN) study. *Diabetes Care* 29 (6): 1249-1255.
- Ryan, A. M., G. C. Gee, and D. Griffith. 2008. The effects of perceived discrimination on diabetes management. *Journal of Health Care for the Poor and Underserved* 19: 149-163.

- Saggers, S., and D. Gray. 2007. Defining what we mean. In *Social determinants of Indigenous health*, ed. B. Carson, T. Dunbar, R. D. Chenhall and R. Bailie, 1-20. Crows Nest, New South Wales: Allen & Unwin.
- Sandelowski, M. 2004. Using qualitative research. *Qualitative Health Research* 14: 1366-1386.
- Savoca, M. R., C. K. Miller, and S. A. Quandt. 2004. Profiles of people with type 2 diabetes mellitus: The extremes of glycemic control. *Social Science & Medicine* 58: 2655-2666.
- Schillinger, D., K. Grumbach, J. Piette, F. Wang, D. Osmond, C. Daher, J. Palacios, G. Diaz Sullivan, and A. B. Bindman. 2002. Association of health literacy with diabetes outcomes. *JAMA* 288 (4): 475-482.
- SCRGSP. 2009. *Overcoming Indigenous disadvantage: Key indicators 2009*. Canberra: Productivity Commission.
- Selby, J. V., B. E. Swain, R. B. Gerzoff, A. J. Karter, B. E. Waitzfelder, A. F. Brown, R. T. Ackermann, O. K. Duru, A. Ferrara, W. Herman, D. G. Marrero, D. Caputo, and K. M. Venkat Narayan. 2007. Understanding the gap between good process of diabetes care and poor intermediate outcomes: Translating Research Into Action for Diabetes (TRIAD). *Medical Care* 45 (12): 1144-1153.
- Sen, A. 1987. *Commodities and capabilities*. New Delhi: Oxford University Press.
- Shortus, T. D., S. H. McKenzie, L. A. Kemp, J. G. Proudfoot, and M. F. Harris. 2007. Multidisciplinary care plans for diabetes: How are they used? *Medical Journal of Australia* 187 (2): 78-81.
- Siccama, C. J., and S. Penna. 2008. Enhancing validity of a qualitative dissertation research study by using NVivo. *Qualitative Research Journal* 8 (2): 91-103.
- Smith, D. 2004. The population perspective on quality of life among Americans with diabetes. *Quality of Life Research* 13: 1391-1400.
- Solar, O., and A. Irwin. 2007. *A conceptual framework for action on the social determinants of health: Discussion paper for the Commission on Social Determinants of Health*. Geneva: World Health Organization.
- Sontag, S. 1978. *Illness as metaphor*. New York: Farrar, Straus & Giroux.
- Stone, M., E. Pound, A. Pancholi, A. Farooqi, and K. Khunti. 2005. Empowering patients with diabetes: A qualitative primary care study focusing on South Asians in Leicester, UK. *Family Practice* 22: 647-652.
- Strine, T. W., C. A. Okoro, D. P. Chapman, G. L. A. Beckles, L. Balluz, and A. H. Mokdad. 2005. The impact of formal diabetes education on the preventive health practices and behaviors of persons with type 2 diabetes. *Preventive Medicine* 41: 79-84.

- Strong, K., C. Mathers, J. Epping-Jordan, and R. Beaglehole. 2006. Preventing chronic disease: A priority for global health. *International Journal of Epidemiology* 35 (2): 492-493.
- Tabrizi, J. S., A. J. Wilson, E. T. Coyne, and P. K. O'Rourke. 2007. Clients' perspective on service quality for type 2 diabetes in Australia. *Australian and New Zealand Journal of Public Health* 31 (6): 511-515.
- Tabrizi, J. S., A. J. Wilson, E. T. Coyne, and P. K. O'Rourke. 2008. Review of patient-reported type 2 diabetes service quality. *Australian Health Review* 32 (1): 23-33.
- Tamwoy, E., M. Haswell-Elkins, M. Wong, W. Rogers, P. d'Abbs, and R. McDermott. 2004. Living and coping with diabetes in the Torres Strait and Northern Peninsula area. *Health Promotion Journal of Australia* 15: 231-236.
- Tang, T. S., M. B. Brown, M. M. Funnell, and R. M. Anderson. 2008. Social support, quality of life, and self-care behaviours among African Americans with type 2 diabetes. *The Diabetes Educator* 34 (2): 266-276.
- Thoits, P. A. 1995. Stress, coping, and social support processes: Where are we? *Journal of Health and Social Behavior* (Extra Issue): 53-79.
- Thomas, M. C., A. J. Weekes, O. J. Broadley, M. E. Cooper, and T. H. Mathew. 2006. The burden of chronic kidney disease in Australian patients with type 2 diabetes (the NEFRON study). *Medical Journal of Australia* 185: 140-144.
- Thompson, S. J., and S. M. Gifford. 2000. Trying to keep a balance: The meaning of health and diabetes in an urban Aboriginal community. *Social Science & Medicine* 51: 1457-1472.
- Thomson, N., A. MacRae, J. Burns, M. Catto, O. Debuyst, I. Krom, R. Midford, C. Potter, K. Ride, S. Stumpers, and B. Urquart. 2010. *Overview of Australian Indigenous health status, April 2010*. Perth, Western Australia: Australian Indigenous HealthInfoNet.
- Thow, A., and A.-M. Water. 2005. *Diabetes in culturally and linguistically diverse Australians: Identification of communities at high risk*. AIHW cat. no. CVD 30. Canberra: Australian Institute of Health and Welfare.
- Tobias, M., and L.-C. Yeh. 2007. How much does health care contribute to health inequality in New Zealand? *Australian and New Zealand Journal of Public Health* 31 (3): 207-210.
- Tong, B., and C. Stevenson. 2007. *Comorbidity of cardiovascular disease, diabetes and chronic kidney disease in Australia*. Cat. no. CVD 37. Canberra: Australian Institute for Health and Welfare.
- Townshend, T., and A. Lake. 2009. Obesogenic urban form: Theory, policy and practice. *Health & Place* 15 (4): 909-916.
- Tsang, A., M. W. Ndungu, J. Coveney, and L. O'Dwyer. 2007. Adelaide Healthy Food Basket: A survey on food cost, availability and affordability in five

- local government areas in metropolitan Adelaide, South Australia. *Nutrition & Dietetics* 64 (4): 241-247.
- Turrel, G., B. Hewitt, C. Patterson, B. Oldenburg, and T. Gould. 2002. Socioeconomic differences in food purchasing behaviour and suggested implications for diet-related health promotion. *Journal of Human Nutrition & Dietetics* 15: 355-364.
- Turrel, G., L. Stanley, M. de Looper, and B. Oldenberg. 2006. *Health inequalities in Australia: Morbidity, health behaviours, risk factors and health service use. Health Inequalities Monitoring Series No. 2. AIHW Cat. No. PHE 72.* Canberra: Queensland University of Technology and the Australian Institute of Health and Welfare.
- Tyrrell, M., J. Grundy, P. Lynch, and J. Wakerman. 2003. Laramba diabetes project: An evaluation of a participatory project in a remote Northern Territory community. *Health Promotion Journal of Australia* 14: 48-53.
- UNDP. 2010. *Human development report 2010. The real wealth of nations: Pathways to human development.* New York: Palgrave MacMillan.
- United Nations General Assembly. 1948. *Universal Declaration of Human Rights.* Paris: United Nations.
- Utz, S. W., R. H. Steeves, J. Wenzel, I. Hinton, R. A. Jones, D. Andrews, A. Muphy, and N. Oliver. 2006. "Working hard with it": Self-management of type 2 diabetes by rural African Americans. *Family and Community Health* 29 (3): 195-205.
- Vågerö, D. 1995. Health inequalities as policy issues: Reflections on ethics, policy and public health. *Sociology of Health & Illness* 17 (1): 1-19.
- van Kippersluis, H., O. O'Donnell, E. van Doorslaer, and T. Van Ourti. 2010. Socioeconomic differences in health over the life cycle in an egalitarian country. *Social Science & Medicine* 70: 428-438.
- Van Ryn, M., and J. Burke. 2000. The effect of patient race and socioeconomic status on physicians' perceptions of patients. *Social Science & Medicine* 50: 813-828.
- WADoH. 2008. *Diabetes Model of Care.* Perth: Health Networks Branch, Department of Health, Western Australia.
- Walter, M., and S. Siggers. 2007. Poverty and social class. In *Social determinants of Indigenous health*, ed. B. Carson, T. Dunbar, R. D. Chenhall and R. Bailie, 87-107. Crows Nest, New South Wales: Allen & Unwin.
- Warr, D. J. 2005. "It was fun... but we don't usually talk about these things": Analyzing sociable interaction in focus groups. *Qualitative Inquiry* 11 (2): 200-225.

- Wellard, S. J., S. Rennie, and R. King. 2008. Perceptions of people with type 2 diabetes about self-management and the efficacy of community based services. *Contemporary Nurse* 29 (2): 218-226.
- Whitehead, M. 1991. The concepts and principles of equity and health. *Health Promotion International* 6 (3): 217-228.
- WHO. 2003. *Social determinants of health: The solid facts*. Edited by R. Wilkinson and M. Marmot. 2nd ed. Copenhagen: WHO.
- WHO. 2004. *Global strategy on diet, physical activity and health*. Geneva: World Health Organization.
- WHO. 2005a. *Preventing chronic diseases: A vital investment*. [http://www.who.int/chp/chronic\\_disease\\_report/en/index.html](http://www.who.int/chp/chronic_disease_report/en/index.html) (accessed March 20, 2008).
- WHO. 2005b. *Rethinking 'diseases of affluence': The economic impact of chronic diseases*. [http://www.who.int/chp/chronic\\_disease\\_report/media/Factsheet4.pdf](http://www.who.int/chp/chronic_disease_report/media/Factsheet4.pdf) (accessed April 4, 2008).
- WHO. 2006. *What is diabetes?* <http://www.who.int/mediacentre/factsheets/fs312/en/index.html> (accessed March 18, 2008).
- WHO. 2008. *Chronic diseases*. [http://www.who.int/topics/chronic\\_diseases/en/](http://www.who.int/topics/chronic_diseases/en/) (accessed August 18, 2008).
- WHO, and IDF. 2006. *Definition and diagnosis of diabete mellitus and intermediate hyperglycaemia: Report of a WHO/IDF consultation*. Geneva: World Health Organization.
- WHO Europe. 2006. *Tackling Europe's major diseases: The challenges and the solutions [factsheet EURO/03/06]*. <http://www.euro.who.int/document/mediacentre/fs0306e.pdf> (accessed August 27, 2008).
- Wild, S., G. Roglic, A. Green, R. Sicree, and H. King. 2004. Global prevalence of diabetes: Estimates for the year 2000 and projections for 2030. *Diabetes Care* 27: 1047-53.
- Wilkinson, R. G. 2005. *The impact of inequality: How to make sick societies healthier*. New York: The New Press.
- Williams, A. F., E. Manias, and R. Walker. 2008. Adherence to multiple, prescribed medications in diabetic kidney disease: A qualitative study of consumers' and health professionals' perspectives. *International Journal of Nursing Studies* 45: 1742-1756.
- Willis, K., J. Daly, M. Kealy, R. Small, G. Koutroulis, J. Green, L. Gibbs, and S. Thomas. 2007. The essential role of social theory in qualitative public health



research. *Australian and New Zealand Journal of Public Health* 31 (5): 438-43.

Winkler, E., G. Turrell, and C. Patterson. 2006. Does living in a disadvantaged area entail limited opportunities to purchase fresh fruit and vegetables in terms of price, availability, and variety? Findings from the Brisbane Food Study. *Health & Place* 12 (4): 741-748.

Wood, L., T. Shannon, M. Bulsara, T. Pikora, G. McCormack, and B. Giles-Corti. 2008. The anatomy of the safe and social suburb: An exploratory study of the built environment, social capital and residents' perceptions of safety. *Health & Place* 14: 15-31.

Yu, V. L., and D. Raphael. 2004. Identifying and addressing the social determinants of the incidence and successful management of type 2 diabetes mellitus in Canada [commentary]. *Revue Canadienne de Sante Publique* 95 (5): 366-368.

Zimmerman, M., J. B. McGlinchey, D. Young, and I. Chelminski. 2006. Diagnosing major depressive disorder III: Can some symptoms be eliminated from the diagnostic criteria? *Journal of Nervous and Mental Disease* 194: 313-317.

Zimmet, P. 2000. Globalization, coca-colonization and the chronic disease epidemic: Can the Doomsday scenario be averted? *Journal of Internal Medicine* 247 (3): 301-310.

Zoffmann, V., I. Harder, and M. Kirkevold. 2008. A person-centered communication and reflection model: Sharing decision-making in chronic care. *Qualitative Health Research* 18 (5): 670-685.

*Every reasonable effort has been made to acknowledge the owners of copyright material. I would be pleased to hear from any copyright owner who has been omitted or incorrectly acknowledged.*



# Appendix 1 – Consent Form



*Living with Type 2 Diabetes*  
Curtin University Study on the Impact of Type 2 Diabetes

## PARTICIPANT CONSENT FORM

I, \_\_\_\_\_ have read the information provided, and any questions I have asked have been answered to my satisfaction.

I agree to participate in this study, realising that I may withdraw at any time without having to give any reason and without any negative impact.

I understand that all information provided is treated as strictly confidential and will not be released by the researcher unless required by law. I have been advised as to what data is being collected, what the purpose is, and what will be done with the data at the end of the study.

I agree that research data gathered for the study may be published provided my name or other identifying information is not used.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date

*Additional information on the study can be obtained from Beatriz Cuesta Briand on (08) 9266 3170 or [beatriz.cuestabriand@postgrad.curtin.edu.au](mailto:beatriz.cuestabriand@postgrad.curtin.edu.au).*

*'Living with Type 2 Diabetes' – Consent Form*



# Appendix 2a – Information Sheet Focus Group



*Living with Type 2 Diabetes*  
Curtin University Study on the Impact of Type 2 Diabetes

## PARTICIPANT INFORMATION SHEET

I am Beatriz Cuesta Briand, and I am doing research on how type 2 diabetes affects those who have it, their family members and others around them. We know from other research that personal, family, work and financial circumstances have an impact on how people manage their diabetes. I am interested in finding out how people manage their disease, and how their disease is managed by their doctors and other health professionals, for example nurses, eye specialists or dieticians. Also, I am interested in finding out what people living with diabetes think about the care they receive and what could be done to improve their quality of life.

The aim of the study is to understand the family, work and financial implications of living with type 2 diabetes so that more effective ways of managing the disease can be implemented by health service providers.

If you would like to take part in this study, you can come along to a one-hour group session that will include a maximum of 8 people. The group session will be held at **Sudbury Community House** in Mirrabooka (30 Chesterfield Rd; corner of Sudbury & Chesterfield Rds) on **Tuesday, October 28, from 10.30 to 11.30am**.

During the session you will be invited to talk about your experience and how diabetes impacts on your life. You will also be asked to provide some basic information about yourself, such as your age, gender, etc, and a few simple questions about your diagnosis. You do not need to reveal anything you are not comfortable about. Because we will be discussing issues that have to do with your illness, what supports you have, how you manage, etc, you could find that something that is discussed upsets you. If something upsets you there will be an opportunity to discuss it at the end of the session and information on counselling will be available if you require it. The session will be recorded on an audiotape so that the information collected can be analysed later on.

In recognition of your contribution to the study and to compensate you for your time and effort, you will be paid \$30 if you decide to take part in the study.

The information collected during the study will be stored securely and kept confidential. All personal information will be kept only for as long as it is needed, and then will be destroyed. Information will not be reproduced in a manner that could lead to the identification of any of the participants. Once the study is completed, a summary of the findings will be sent to all participants. The results of the study will also be circulated to the wider community, including the community health centres located in the area included in the study. Participants will not be named in any of the reports that are produced as part of the study.

If you agree to participate in the study you will be able to withdraw at any time, and you do not have to give a reason for doing so. If you withdraw from the study, all the information provided by you will be destroyed.

*'Living with Type 2 Diabetes' – Information Sheet Focus Groups*

If you are interested in taking part but would like to ask some questions about what is involved, please do not hesitate to give me a ring. I can be reached on (08) 9266 3170, or you can contact my supervisor, Professor Sherry Sagers, on (08) 9266 1605.

*This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 95/2008). If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845, or by telephoning 9266 2784 or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au).*

*'Living with Type 2 Diabetes' – Information Sheet Focus Groups*

# Appendix 2b – Information Sheet Indigenous Focus Group

Health Sciences



*Living with Type 2 Diabetes*  
Curtin University Study on the Impact of Type 2 Diabetes

## PARTICIPANT INFORMATION SHEET

I am Beatriz Cuesta Briand, and I am doing research on how type 2 diabetes affects those who have it, their family members and others around them. We know from other research that personal, family, work and financial circumstances have an impact on how people manage their diabetes. I am interested in finding out how people manage their disease, and how their disease is managed by their doctors and other health professionals, for example nurses, eye specialists or dieticians. Also, I am interested in finding out what people living with diabetes think about the care they receive and what could be done to improve their quality of life.

The aim of the study is to understand the family, work and financial implications of living with type 2 diabetes so that more effective ways of managing the disease can be implemented by health service providers.

If you would like to take part in this study, you can come along to a one-hour group session that will include a maximum of 8 people. The group session will be held at **Derbarl Yerrigan Health Service in Mirrabooka** (22 Chesterfield Rd) on **Wednesday, October 22, from 10.00 to 12.00am**.

During the session you will be invited to talk about your experience and how diabetes impacts on your life. You will also be asked to provide some basic information about yourself, such as your age, gender, etc, and a few simple questions about your diagnosis. You do not need to reveal anything you are not comfortable about. Because we will be discussing issues that have to do with your illness, what supports you have, how you manage, etc, you could find that something that is discussed upsets you. If something upsets you there will be an opportunity to discuss it at the end of the session and information on counselling will be available if you require it. The session will be recorded on an audiotape so that the information collected can be analysed later on.

In recognition of your contribution to the study and to compensate you for your time and effort, you will be paid \$30 if you decide to take part in the study.

The information collected during the study will be stored securely and kept confidential. All personal information will be kept only for as long as it is needed, and then will be destroyed. Information will not be reproduced in a manner that could lead to the identification of any of the participants. Once the study is completed, a summary of the findings will be sent to all participants. The results of the study will also be circulated to the wider community, including the community health centres located in the area included in the study. Participants will not be named in any of the reports that are produced as part of the study.

If you agree to participate in the study you will be able to withdraw at any time, and you do not have to give a reason for doing so. If you withdraw from the study, all the information provided by you will be destroyed.

*'Living with Type 2 Diabetes' – Information Sheet Indigenous Focus Group*

If you are interested in taking part but would like to ask some questions about what is involved, please do not hesitate to give me a ring. I can be reached on (08) 9266 3170, or you can contact my supervisor, Professor Sherry Sagers, on (08) 9266 1605.

*This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 95/2008). If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845, or by telephoning 9266 2784 or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au).*

*'Living with Type 2 Diabetes' – Information Sheet Focus Groups*



## Appendix 2c – Information Sheet Interviews



*Living with Type 2 Diabetes*  
Curtin University Study on the Impact of Type 2 Diabetes

### PARTICIPANT INFORMATION SHEET

I am Beatriz Cuesta Briand, and I am doing research on how type 2 diabetes affects those who have it, their family members and others around them. We know from other research that personal, family, work and financial circumstances have an impact on how people manage their diabetes. I am interested in finding out how people manage their disease, and how their disease is managed by their doctors and other health professionals, for example nurses, eye specialists or dieticians. Also, I am interested in finding out what people living with diabetes think about the care they receive and what could be done to improve their quality of life.

The aim of the study is to understand the family, work and financial implications of living with type 2 diabetes so that more effective ways of managing the disease can be implemented by health service providers.

If you would like to be part of this study, you can take part in a face-to-face interview that will last for about an hour and that will be conducted either at your home or at any other location that is convenient to you. The interviews will take place during 2009, and you can choose the date and time that suit you best.

During the interview you will be invited to talk about your experience and how diabetes impacts on your life. You will also be asked to provide some basic information about yourself, such as your age, gender, etc, and a few simple questions about your diagnosis. You do not need to reveal anything you are not comfortable about. Because we will be discussing issues that have to do with your illness, what supports you have, how you manage, etc, you could find that something that is discussed upsets you. If something upsets you there will be an opportunity to discuss it at the end of the session and information on counselling will be available if you require it. The session will be recorded on an audiotape so that the information collected can be analysed later on.

In recognition of your contribution to the study and to compensate you for your time and effort, you will be paid \$30 if you decide to take part in the study.

The information collected during the study will be stored securely and kept confidential. All personal information will be kept only for as long as it is needed, and then will be destroyed. Information will not be reproduced in a manner that could lead to the identification of any of the participants. Once the study is completed, a summary of the findings will be sent to all participants. The results of the study will also be circulated to the wider community, including the community health centres located in the area included in the study.

If you agree to participate in the study you will be able to withdraw at any time, and you do not have to give a reason for doing so. If you withdraw from the study, all the information provided by you, including the taped interview, will be destroyed.

*'Living with Type 2 Diabetes' – Information Sheet Interviews*

If you are interested in taking part but would like to ask some questions about what is involved, please do not hesitate to give me a ring. I can be reached on (08) 9266 3170, or you can contact my supervisor, Professor Sherry Sagers, on (08) 9266 1605.

*This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 95/2008). If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845, or by telephoning 9266 2784 or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au).*

*'Living with Type 2 Diabetes' – Information Sheet Interviews*

## Appendix 3 – IRSD Variables

Variables included in the Index of Relative Socio-economic Disadvantage (IRSD).

<b>Dimension</b>	<b>Variable</b>	<b>Variable Description</b>
Income	Low Income	% People with stated annual household equivalised income between \$13,000 and \$20,799
Education	No Qualifications	% People aged 15 years and over with no post-school qualifications
	No School	% People aged 15 years and over who did not go to school
Employment	Unemployed	% People in the labour force who are unemployed
Occupation	Machinery Operators and Drivers	% Employed people classified as Machinery Operators and Drivers
	Labourers	% Employed people classified as Labourers
	Low-Skill Community and Personal Service Workers	% Employed people classified as Low-Skill Community and Personal Service Workers
Housing	Low Rent	% Households paying rent who pay less than \$120 per week
	Overcrowding	% Occupied private dwellings requiring one or more extra bedrooms
	Social Rent	% Households renting dwelling from a government or community organisation
Other	Disability under 70	% People aged under 70 who need assistance with core activities due to a long-term health condition, disability or old age
	Poor English	% People who do not speak English well
	Indigenous	% People who identified themselves as being of Aboriginal and/or Torres Strait Islander origin
	No Car	% Occupied private dwellings with no cars
	No Net	% Occupied private dwellings with no Internet connection
	One Parent Families	% Families that are one parent families with dependent offspring only
	Divorced	% People aged 15 and over who are separated or divorced

Source: ABS (2008d).



## Appendix 4 – Focus Group Recruitment Flyer

# LIVING WITH TYPE 2 DIABETES?

*Have you been told by your doctor that you  
have type 2 diabetes?*

*Does diabetes affect your personal life?  
Your work? Your finances?*

*Do you live in Mirrabooka, Nollamara, Balga  
or Westminster?*

Curtin University of Technology is doing research to find out **what it means to live with type 2 diabetes**, the effect it has on you and your family, and how you manage your diabetes, including the care you receive from your doctor.

We hope that the results of our study will help understand the impact of type 2 diabetes on people's personal lives, families, work and finances so that those affected can be better supported.

You can get involved in the study by attending **a group interview that will be held in Mirrabooka in the next few weeks**. You will have the opportunity to talk about your experience and have your say about what you think could be done to improve the lives of people living with diabetes.

If you decide to take part in the study you will be paid \$30 to compensate you for your time and your contribution.

**To find out more about the study and to register, ring Beatriz  
on 9266 3170 before October 17. Places are limited.**

Health Sciences





## Appendix 5 – Indigenous Focus Group Recruitment Flyer

Health Sciences | **Curtin**  
University of Technology

Looking for Aboriginal  
People with (type 2) diabetes  
in the Mirrabooka, Nollamara,  
Balga and Westminster Areas,  
to be part of a Focus Group

When: Wed 22 October, 2008  
10:00am to 12:00pm

Where: Derbarl Yerrigan Health Service,  
Mirrabooka (Conference Room)

Lunch will be provided and  
payment of \$30 for your input

If you would like to know more about  
the focus group or would like to  
RSVP please contact  
Tracey Kickett on 6464 0602

 **diabeteswa**  
Freedom from Diabetes

 **DON'T  
IGNORE  
DIABETES**



Does diabetes affect your personal life?  
Your Work? Your finances?

Curtin University is doing research to find out what it means to live with type 2 diabetes, the effect it has on you and your family, and how you manage your diabetes, including the care you receive from your doctor.

We hope that the results of our study can assist in providing better support.

You will have the opportunity to talk about your experience and have your say about what you think could be done to improve the lives of people living with diabetes.

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## Appendix 6 – Interview Recruitment Flyer

# LIVING WITH TYPE 2 DIABETES?

*Have you been told by your doctor that you have  
type 2 diabetes?*

*Does diabetes affect your personal and family  
life? Your work? Your budget?*

*Do you live in Balga, Mirrabooka, Nollamara or  
Westminster?*

Curtin University of Technology is doing research to find out **what it means to live with type 2 diabetes** and how you manage your diabetes, including the care you receive from your doctor.

We hope that the results of our study will help to understand the impact of type 2 diabetes on people's personal lives, families, work and finances so that those affected can be better supported.

**We will be interviewing people living with type 2 diabetes during 2009.** Interviews will last for about an hour and participants will be asked to talk about what it is like to live with diabetes. Participants will receive \$30 to compensate them for their time and contribution.

**To find out more about the study or to book an interview,  
ring Beatriz on 9266 3170.**

Health Sciences





## Appendix 7 – Newspaper Advertisements

First round of interviews

### University diabetes study

RESIDENTS of Balga, Mirrabooka, Nollamara and Westminster with Type 2 diabetes are the target of a recent study on how the condition affects their lives.

Researchers from Curtin University of Technology want to interview these people about how the condition has affected their family, work and finances.

The interviews take about an hour and participants will receive \$30 to compensate for their time and contribution.

Eligible people for the study must have been diagnosed with Type 2 diabetes for at least a year and be aged 18 or over. To take part, call Beatriz on 92663170.

Second round of interviews

### Diabetes dialogue

CURTIN University of Technology researchers would like to interview people with type two diabetes about how the condition affects their lives.

To take part in the research, participants must have been diagnosed with type two diabetes for at least a year, live in Balga, Mirrabooka, Nollamara or Westminster and be at least 18 years old.

The interviews take about an hour and people who take part will receive \$30.

While researchers are keen to speak to people from any age group, they would particularly like to interview people aged in their mid-50s or younger.

The researchers are hoping to find ways to improve the health services and support people with type two diabetes receive.

For more information or to take part in the study, call Beatriz on 9266 3170.




# Appendix 8 – HCC & Diabetes WA Advertisements

## HCC Advertisement

### Type 2 diabetes research to improve health services and support

Perth researchers want to interview people with type 2 diabetes to understand how the condition affects their lives.

The researchers, from Curtin University of Technology, are looking for ways to improve the health services and support people with type 2 diabetes receive.



Researcher Beatriz Cuesta Briand

"We want to understand how living with type 2 diabetes affects people's personal lives, their families, their work and their finances," researcher Beatriz Cuesta Briand said.

"Through talking to people with type 2 diabetes about their experience, we can hopefully find better ways to support them, including making suggestions as to how health services can be more responsive to their needs."

An estimated 840,000 Australians have type 2 diabetes, or 7% of the adult population. According to 'Diabetes: Australian Facts 2005', published by the Australian Institute of Health and Welfare, the proportion of people with diabetes more than doubled between 1989 and 2005. The rise is largely driven by an increase in the prevalence of type 2 diabetes.

The report found that some groups, such as the least well-off and Indigenous Australians, were more likely to develop diabetes, and had significantly higher diabetes hospitalisation and death rates than the general population.

Beatriz's study is examining the link between disadvantage and type 2 diabetes. Research interviews will focus on four northern Perth suburbs - Balga, Mirrabooka, Nollamara and Westminster. Focus groups have already been conducted in Mirrabooka in the first phase of the study.

"People who are less well off are at higher risk of developing type 2 diabetes," Beatriz said. "Once they have developed diabetes, they are less likely to access health services to help manage their condition".

"If we can understand why through our interviews, we may then be able to help prevent people developing serious complications from type 2 diabetes and improve the support those with the condition receive, particularly those who are more disadvantaged."

To take part in the research, participants must have been diagnosed with type 2 diabetes for at least a year, live in Balga, Mirrabooka, Nollamara or Westminster, and be at least 18 years old. People who take part in the interviews will receive \$30 to compensate them for their time and contribution. The interviews take about an hour and can be completed in the participant's home or another location of their choosing. The study has been undertaken in collaboration with Diabetes WA, and with the support of Derbarl Yerrigan Health Service and community-based support groups.

To find out more about the study or to organise an interview, contact Beatriz Cuesta Briand on 9266 3170 or [beatriz.cuestabriand@postgrad.curtin.edu.au](mailto:beatriz.cuestabriand@postgrad.curtin.edu.au).

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## LIVING WITH TYPE 2 DIABETES?

*Have you been told by your doctor that you have type 2 diabetes?*

*Does diabetes affect your personal and family life? Your work? Your budget?*


*Do you live in Balga, Mirrabooka, Nollamara or Westminster?*

Curtin University of Technology is doing research to find out what it means to live with type 2 diabetes and how you manage your diabetes, including the care you receive from your doctor.

We hope that the results of our study will help to understand the impact of type 2 diabetes on people's personal lives, families, work and finances so that those affected can be better supported.

We will be interviewing people living with type 2 diabetes during 2009. Interviews will last for about an hour and participants will be asked to talk about what it is like to live with diabetes. Participants will receive \$30 to compensate them for their time and contribution.


*To find out more about the study or to book an interview, ring Beatriz on 9266 3170.*

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## Diabetes WA Advertisement

### Interviewees Wanted for type 2 Diabetes Study



Beatriz Cuesta

Researchers are looking for people with type 2 diabetes to participate in an interview about how the condition affects their lives. Conducted by a PhD student from Curtin University of Technology, this study aims to understand the impact of type 2 diabetes on people's lives so that those affected can be better supported.

Participants must have a clinical diagnosis for at least a year, live in Balga, Mirrabooka, Nollamara or Westminster and be aged 18 years or over. The interviews will take approximately one hour and participants will receive a \$30 compensation for their time.

"We want to understand how living with type 2 diabetes affects people's personal lives, their families, their work and their finances," researcher Beatriz Cuesta Briand said, "By talking to people with type 2 diabetes about their experience, we can hopefully find better ways to support them, including by making sure that health services are providing the help that they need."

The study has been undertaken in collaboration with Diabetes WA, and with the support of Derbarl Yerrigan Health Service and community-based support groups. For more information or to arrange an interview, contact Beatriz on 9266 3170 or email [beatriz.cuestabriand@postgrad.curtin.edu.au](mailto:beatriz.cuestabriand@postgrad.curtin.edu.au)



## Appendix 9 – Thank-you Letter

Health Sciences



[Name]  
[Address]

[Date]

Dear [Name]

I am writing this letter to thank you sincerely for taking part in the *Living with Type 2 Diabetes* study. The objective of the study is to find out how people manage their diabetes, and this cannot be achieved without the contribution of those who, like you, know the disease because they live with it every day.

The response to the study has been very positive so far. I have been doing interviews in the community for the last three months, and I have talked to twenty-six people. I will continue to do interviews in the next couple of months and I will then begin analysing the information I have gathered.

As I mentioned during our interview, I will be sending a summary of findings of the study to all participants once all the interviews have been analysed. This **summary of findings** will contain an overview of the main issues and topics that came out of the interviews, and it will be mailed to you during the course of next year – as soon as it becomes available.

A copy of the **transcript** of our interview is also available. This is a word-by-word written record of our interview. If you are interested in receiving a copy for your records, please contact me and I will mail it to you.

I thank you again for being part of the *Living with Type 2 Diabetes* study. The time you put aside to talk with me about your experience and your contribution are very much appreciated. I hope that the results of the study will contribute to finding ways in which people living with diabetes in the community can be better supported.

Please feel free to contact me if you have any questions about the study, the summary of findings or the transcript. You can ring me on 9266 3170 or email me on [beatriz.cuestabriand@postgrad.curtin.edu.au](mailto:beatriz.cuestabriand@postgrad.curtin.edu.au). I will be happy to answer any questions.

Yours sincerely

Beatriz Cuesta Briand  
PhD Candidate  
*Living with Type 2 Diabetes*





# Appendix 10 – Lay Summary of Results



## ***Living with Type 2 Diabetes*** Curtin University Study on the Impact of Type 2 Diabetes

### **Summary of Results**

#### **What was the research about?**

The research looked at how type 2 diabetes affects people's lives, their families, their work and their budget. In particular, the research looked at:

- how people manage their diabetes every day;
- what medical care they get for their diabetes;
- what they think about the care they receive; and
- what they think could be done to make things better for people with diabetes.

#### **What do we know about diabetes?**

We know from other research that personal, family and financial issues have an impact on how people manage their diabetes. We know that diabetes can have serious complications. We also know that some groups of people (e.g. Aboriginal and Torres Strait Islander people and people who live on low incomes), are more likely to get diabetes.

#### **How was the information collected?**

The information was collected by talking with people who have type 2 diabetes in and around the Mirrabooka area. Those who took part were asked some questions about themselves, and then they were invited to talk about their experience with diabetes.

#### **When was the information collected?**

The information was collected between October 2008 and November 2009.

#### **How many people took part in the research?**

A total of 38 people took part in the research, including Indigenous and non-Indigenous participants, and people born in Australia and in other countries. (Note: as this is a small study, the results cannot be generalised to the whole population).

## Living with Type 2 Diabetes

### What were the main things people talked about?

#### 1. Managing diabetes every day: diet, exercise and medication

##### *Eating the 'right food'*

- Having a healthy diet is very important, but it is hard to give up favourite foods and resist cravings.
- Healthy foods are expensive, particularly fruit, vegetables, meat and low-fat products. It is hard to fit the cost of healthy food in the budget.
- Some depend on others to shop and cook for them, and they don't always have meals that are good for their diabetes.
- Family get-togethers and special occasions like birthdays and Christmas are times when it is especially hard to stick to the diet.



*Participants' tips: use spray oil; use water instead of oil as a base for cooking; put mince in the grill to drain the fat. To reduce your portions, use a smaller plate. Save money by splitting the cost of items on special with a neighbour.*

##### *The challenges of exercise*

- It is important to exercise, but it is hard to find the motivation to do it.
- Many participants said they have health problems that make it harder to exercise.
- Some said they want to go the gym or the pool, but it's expensive.
- Three participants said they don't feel safe going for walks.



*Participants' tips: exercise with a friend; go for a longer walk; find out about exercise groups in your community.*

##### *Taking medications*

- Most said taking tablets is part of their daily routine, but some said they forget to take them sometimes.
- Some participants said they feel frustrated about taking many medications, and they worry about possible side-effects.
- Those on insulin said they were frightened the first time they injected themselves, and some found it hard to plan their lives around the needles.
- Participants said there is stigma associated with using needles.



*Participants' tips: use a dispenser or Webster pak®; keep all the tablets together on the kitchen counter; carry extra tablets in your bag in case you need them. If you are on insulin and you go out shopping, choose shopping centres where you know the toilets are clean.*

## Living with Type 2 Diabetes

### 2. Living with diabetes

- The hardest thing about diabetes is feeling tired and having no energy.
- Having sore or burning feet is also common.
- Some people said they feel emotional, frustrated and short-tempered.
- Most said diabetes runs in their family, and many said they are frightened of the complications of diabetes, because they have seen family members suffer from them.
- Stress and worry are bad for diabetes. Many worry about their families or about money, and some said they have depression.
- Many participants said other people don't understand what it's like to have diabetes. Some said even their family members can't accept their illness.



*Participants' tips: reduce your stress levels by talking to friends and neighbours; join a support group; meditate; listen to music; have some 'me' time.*

### 3. Medical care of diabetes

#### *Accessing health services*

- Most participants said their GP checks their diabetes, but some said they don't see their GP regularly. Most participants on insulin said they see a specialist once a year.
- Few people said they have their feet checked by a podiatrist – some thought there is no need and others said it is very expensive.
- Most participants said they have their eyes tested regularly.

#### *Opinions on the quality of care*

- For participants, a good doctor is somebody who is understanding, a good listener, and who takes the time to know the person.
- Some were happy with their doctors, but others weren't satisfied. Some said they had bad experiences with doctors and dietitians.
- Participants said the medical consultations are rushed, and some were frustrated about the lack of support they received from their doctors.
- People thought the diabetes education sessions are useful, but the information is overwhelming. They agreed that everybody is different and that the information has to be adapted to the needs of the person.



*Participants' tips: talk to your doctor; ask questions; if you're not happy with your doctor, go to another one and ask for a second opinion.*

## ***Living with Type 2 Diabetes***

### **4. Priorities for a better quality of life**

- Most people wanted local services and support groups that were easy to access where they could receive support from health professionals and from other people with diabetes.
- Many wanted more information on available services, and suggested to have more information displayed in places like chemists and GP surgeries.
- People wanted children to be educated about the disease at school, and they also wanted the community to know more about diabetes as many said: '*people don't understand*'.

\*\*\*\*\*

### **What happens next?**

The results of the study will be sent to Diabetes WA, the WA Department of Health, the Health Consumers' Council of WA, and to community and Aboriginal health centres. The results will also be presented at conferences and they will be published in scientific papers.

### **What is the benefit to participants and the community?**

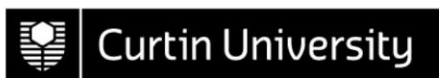
We hope that the results of this research will help health and community services understand what living with diabetes is like so that they can support people with diabetes better.



*For more information on the study, contact Beatriz Cuesta-Briand on 9266 3170 or [beatriz.cuestabriand@postgrad.curtin.edu.au](mailto:beatriz.cuestabriand@postgrad.curtin.edu.au).*

*For information on diabetes and support groups available in your area, contact Diabetes WA on 1300 136 588 (Diabetes WA Information and Advice Line).*

**Thank you to all participants for contributing to the research!**



# Appendix 11 – Background Questionnaire

Health Sciences



## *Living with Type 2 Diabetes*

Curtin University Study on the Impact of Type 2 Diabetes

Please complete the following questions:

### ABOUT YOU:

1. What is your name? \_\_\_\_\_
  
2. What is your age in years? 18-24  25-34  35-44  45-54   
(please tick one box) 55-64  65-74  75-84  85+
  
3. Are you? Female  Male
  
4. Do you have a partner/spouse? Yes  No
  
5. Do you have dependent children living with you? Yes  No   
 5a. If your answer is yes, how many? \_\_\_\_\_
  
6. Are you of Aboriginal and/or Torres Strait Islander background? Yes, Aboriginal  Yes, both   
Yes, TSI  No
  
7. In what country were you born? \_\_\_\_\_
  
8. What is the **highest** year of education you have **completed**? (please tick one box)  

Never attended school <input type="checkbox"/>	Year 8 or below <input type="checkbox"/>	Year 9 <input type="checkbox"/>
Year 10 <input type="checkbox"/>	Year 11 <input type="checkbox"/>	Year 12 <input type="checkbox"/>
TAFE Certificate <input type="checkbox"/>	Bachelor Degree <input type="checkbox"/>	Postgraduate Degree <input type="checkbox"/>
  
9. What is your occupation? \_\_\_\_\_
  
10. What is your **gross weekly** household income? (please tick one box)  

\$1-\$199 <input type="checkbox"/>	\$600-\$799 <input type="checkbox"/>	\$1,200-\$1,399 <input type="checkbox"/>
\$200-\$399 <input type="checkbox"/>	\$800-\$999 <input type="checkbox"/>	\$1,400 or more <input type="checkbox"/>
\$400-\$599 <input type="checkbox"/>	\$1,000-\$1,199 <input type="checkbox"/>	

OR

What is your **gross yearly** household income? (please tick one box)

\$1-\$10,399 <input type="checkbox"/>	\$31,200-\$41,599 <input type="checkbox"/>	\$62,400-\$72,799 <input type="checkbox"/>
\$10,400-\$20,799 <input type="checkbox"/>	\$41,600-\$51,999 <input type="checkbox"/>	\$72,800 or more <input type="checkbox"/>
\$20,800-\$31,199 <input type="checkbox"/>	\$52,000-\$62,399 <input type="checkbox"/>	

Continue on the other side...

**ABOUT YOUR DIABETES:**

1. How old were you when you were told that you had diabetes? \_\_\_\_\_
  
2. For how long have you had diabetes (in years)? \_\_\_\_\_
  
3. What medications do you take for your diabetes? (*tick all boxes that apply*)
  - Insulin
  - Glucobay
  - Novonorm
  - Metformin, Diabex, Glucophage, Diaformin, Glucomet or Novomet
  - Diamicron, Diamicron MR, Glyade, Daonil, Glimel, Minidiab, Melizide or Amaryl
  - Avandia or Actos
  - Other – please specify: \_\_\_\_\_  
\_\_\_\_\_
  
4. Please write any other diagnosed health problems, e.g., high blood pressure, high cholesterol, etc.  
\_\_\_\_\_  
\_\_\_\_\_
  
5. Do you take medication for any of your other health problems?    Yes     No

*Thank you for completing these questions*

# Appendix 12 – Focus Group Schedule

Health Sciences



## FOCUS GROUP GUIDE

*Living with Type 2 Diabetes*

Curtin University Study on the Impact of Type 2 Diabetes

### AREAS FOR DISCUSSION

#### Living with & managing your diabetes

- What things do you have to do on a daily basis to manage your diabetes?
- Has your diet changed since you were diagnosed? How? What is the hardest thing when it comes to changing your diet?
- What has your doctor said about exercise? What do you do to exercise?
- Do you take any medication to control your diabetes? What is it like to take medications to control your diabetes? Do you take any medication for other conditions?

#### The medical care of your diabetes

- Whom do you see to check your diabetes, your blood sugar levels, etc? GP? Specialist?
- How often do you see someone about your diabetes?
- Where do you go to have your diabetes checked? How do you get there?
- Do you see any health professionals for your diabetes? Dietician? Foot specialist? Eye specialist? Diabetes educator?
- How do you feel about the care you receive for your diabetes?
- How do you feel about the information you have received about managing your diabetes?

#### The challenges of managing your diabetes

- What is the hardest thing about managing your diabetes? What makes it hard for you to do the things that have been recommended by your doctor?
- What could make living with diabetes and managing your diabetes easier for you?

#### The impact of diabetes on your life

- What is it like living with diabetes? How has it affected you?
- How has it affected your family?
- How has it affected your work? Your finances?

#### Your priorities for a better quality of life

- What does it mean to have a good quality of life? What does it mean to be healthy?
- How do you think health services could make things better for diabetes patients?

**Is there anything else that we haven't covered? Anything else you would like to discuss?**

*'Living with Type 2 Diabetes' – Focus Group Guide*





# Appendix 13 – Interview Schedule



## ***Living with Type 2 Diabetes*** Curtin University Study on the Impact of Type 2 Diabetes

### **INTERVIEW GUIDE**

*First of all I would like to thank you for agreeing to do this interview, which is part of a study looking at the impact of type 2 diabetes on people's lives. I did two group interviews in October last year, and now I'm doing individual interviews with people like you who have type 2 diabetes.*

*The objectives of the study are to find out how people manage their diabetes on a daily basis, what they think about the medical care they receive, and how they think that services for people with diabetes could improve. I hope that the results of the study will help to find ways in which people living with diabetes in the community can be better supported and have a better quality of life.*

*The interview will last for about one hour, and I will be asking you first about how you manage your diabetes on a daily basis, and then about the medical care you receive. After that we will move onto the impact that diabetes has had on your life, and I will finish the interview by asking you your opinion on how to make things better for people living with type 2 diabetes.*

*Do you have any questions before we start?*

*Let's get started.*

***First, I would like to discuss with you how you control your diabetes...***

***Could you describe to me what you have to do on a daily basis to control your diabetes?***

- Diet
  - Has it changed since you were diagnosed? How? Are you eating less? Are you eating healthier food?
  - Has your family diet changed?
  - Where do you shop for food? How do you get there? Public transport? Car? Walking?
  - What is the hardest thing when it comes to your diet?

*'Living with Type 2 Diabetes' – Interview Guide*

- Exercise
  - What has your doctor said about exercise?
  - What do you do to exercise? How often? For how long?
  - Do you go anywhere to exercise? Public park? Swimming pool? Gym? How do you get there? Public transport? Car? Walking?
  - How do you feel about exercise? Do you feel motivated?
- Medication [information on medication will be on background questionnaire]
  - Do you take any medication to control your diabetes? How many times a day? How many tablets a day?
  - Where do you get your prescriptions? Do you have to pay for your medications?
  - Do you take any medication for other conditions?
  - What is it like to have to take medications every day? What is the hardest thing about taking your medication?
- BSL (Blood Sugar Level) monitoring
  - Do you monitor your BSL yourself? How often?
  - Do you have a BSL machine? How did you find out about it?
- Foot Care
  - What has your doctor said about your foot care?
  - How do you take care of your feet? Your toenails?

***Is there anything else you do on a daily basis to control your diabetes?***

*'Living with Type 2 Diabetes' – Interview Guide*

*Let's move on to the medical care of your diabetes...*

*Tell me about the medical care you receive for your diabetes*

- Whom do you see to have your diabetes checked? GP? Specialist? Do you always see the same doctor? Is that important to you (to see the same doctor)?
- What checks do you have done? How often do you have them?
- Where do you go to have your diabetes checked? How do you get there? Public transport? Car? Walking?
- Do you see any other health professionals for your diabetes? Dietician? Foot specialist? Eye specialist? Diabetes educator? How often?

*Tell me about the information you have received on how to manage your diabetes since you were diagnosed*

- What type of information have you received? Leaflets? Other written information? Your GP or specialists talked to you (verbal information)?
- Whom did you get that information from? GP? Specialist? Nurse? Support group?
- What do you think about the information you have received? Was the information helpful? Why? Why not?
- When were you given that information? Did you get the information when you needed it?
- Where do you go if you need more information? GP? Specialist? Nurse? Support group? Internet?

*To finish off this section, I would like to ask you what you think about the quality of the care you receive for your diabetes*

- Are you satisfied with the care you receive for your diabetes? Why? Why not?
  - When you think about the medical care of your diabetes, what is the most important aspect to you? What do you value the most in your GP/Specialist?
  - What is your opinion about your GP/Specialist? Do you feel that you can talk to your GP/Specialist? Do you feel your GP/Specialist understands what you are going through? Has
- 'Living with Type 2 Diabetes' – Interview Guide*

your GP/Specialist referred you or given you information on other support services that are available to you?

- What is your opinion about any other health professionals you see about your diabetes?

***Now I would like to discuss with you the effect that diabetes has had on your life***

***How would you describe what living with diabetes is like to somebody who doesn't know anything about it?***

- What is the hardest thing about living with diabetes?
- What is the hardest thing about managing your diabetes? How do you feel about having to watch your diet? Having to take your medications every day?
- What makes it hard to do the things that your doctor recommends?

***Would you say that your life has changed since you were diagnosed with diabetes?***

- Tell me how diabetes has affected:
  - Your life?
  - Your family?
  - Your work?
  - Your social life?
- When you think of the changes to your diet, the medications you have to take and so on, do you think having diabetes has affected your budget? How?

***Do you have somebody that you can talk to about your diabetes and about the impact that diabetes has had on your life?***

- Whom do you turn to for support? GP? Family? Friends? Support groups? Support services?
- Do you feel that they understand what you're going through? How do you feel about that?

*'Living with Type 2 Diabetes' – Interview Guide*

*To finish our interview, I would like to know your opinion on how to make things better for people living with diabetes...*

*First of all, I would like to ask you what it means to you to have a good quality of life*

- Are there days when you feel physically better/worse? Emotionally better/worse?
  
- What is a good day like for you? What is a bad day like for you?

*What would make living with diabetes easier for you?*

- What would make the biggest difference to your quality of life?

*Finally, when you think about the care you receive for your diabetes, how do you think the health system could make things better for people living with diabetes?*

- How do you think you could be better supported?
  
- How could health services improve? How could information for diabetes patients improve?
  
- What do you think the priorities should be? (More GPs? More specialists? More nurses? More information? Education?)
  
- If you could change one thing about the way the health system works for people living with diabetes, what would it be?

*Is there anything else that we haven't covered? Anything else you would like to talk about?*

*'Living with Type 2 Diabetes' – Interview Guide*



# Appendix 14 – List of Coding Categories

## DATA ANALYSIS – NVIVO NODES

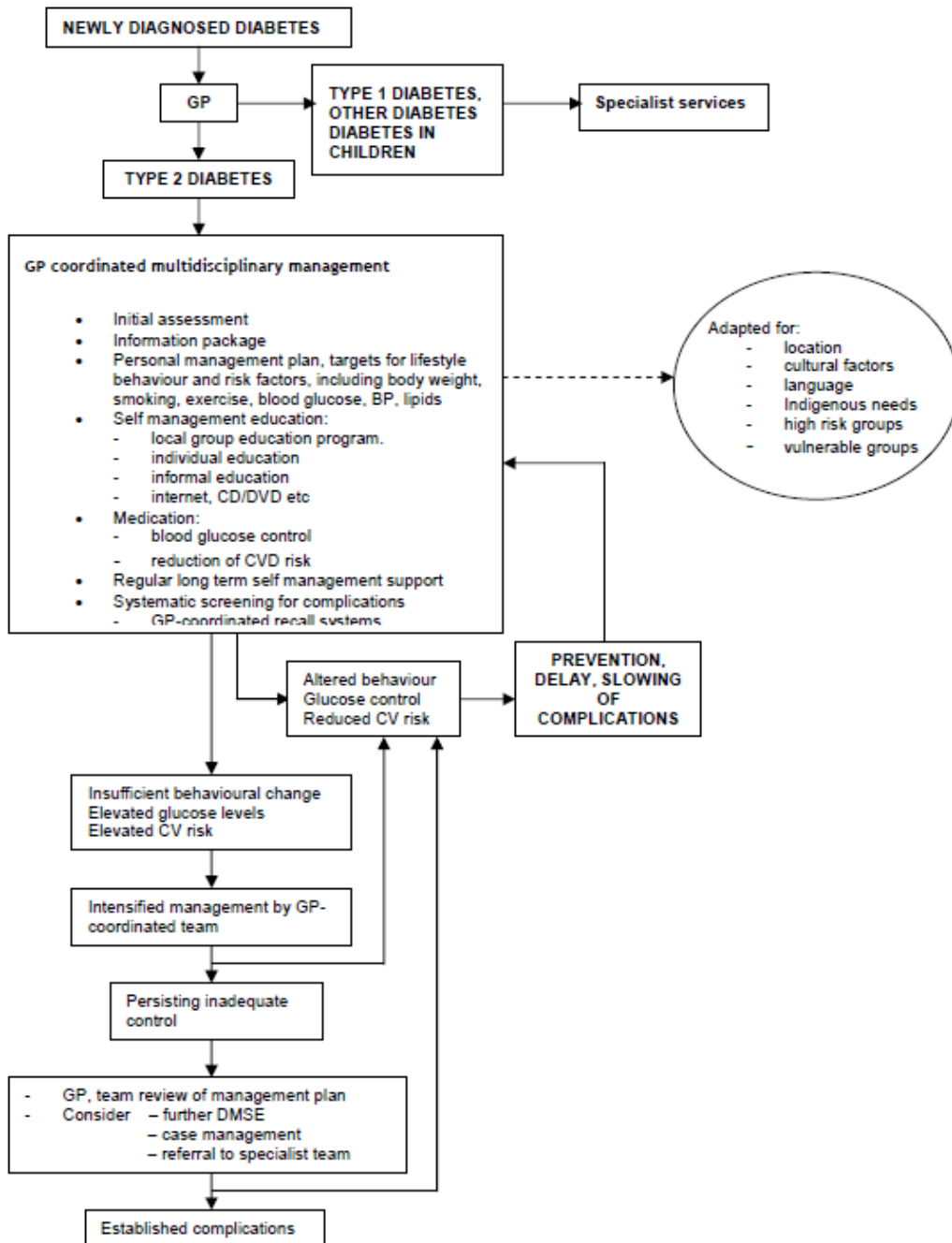
	Level 1 Nodes	Level 2 Nodes	Level 3 Nodes	
<b>SOCIO-ECONOMIC POSITION</b> (Brown et al's) <b>1</b>	SES Individual	Education		
		Income	<i>Budget</i>	
		Occupation		
	SES Community	Wealth		
		<i>Crime &amp; Drugs</i>		
		Education		
<b>PROXIMAL MEDIATORS / MODERATORS</b> (Brown et al's) <b>2</b>	Health Behaviours	Clinical Self-management	BSL Monitoring <i>Foot &amp; Skin Care</i> Medication	
		Lifestyle Factors	<i>AOD</i> Diet Exercise Smoking	
		Access to Care	Primary Health Care	Regular Source of Care Referrals Travel to Appointments
			Specialist Care	Waiting Time
		<i>Other Resources</i>		
	Process	<i>Quality of Care</i>	<i>Provision of Information</i> Regular Monitoring	
	<b>DISTAL MEDIATORS / MODERATORS</b> (Brown et al's) <b>3</b>	Distal Individual	Communication	Language Barriers Health Literacy
			Cultural Factors	<i>Family History</i> <i>Health Beliefs</i>
			<i>Mental Health &amp; Wellbeing</i>	Mental Health <i>Self</i> <i>Self-efficacy</i>
			<i>Social Networks</i>	Competing Demands Social Support
Stress			<i>Disease Progression</i>	
<i>Subjective Experience of Disease</i>			<i>Diagnosis</i>	
Distal Community		Environmental Exposures		
		Healthy Foods		
		Neighbourhood Safety		
		Places to Exercise		
Health Care System		Transport		
		Care Coordination		
		Financial Arrangements		
		Organisational Arrangements		
<b>CRITICAL COVARIATES</b> (Brown et al's) <b>4</b>		Covariates	Self-management Education	
			Age	
	<i>Indigenous Background</i>			
	<i>Ethnic Background</i>			
	Gender			
<b>HEALTH OUTCOMES</b> (Brown et al's) <b>5</b>	Health Outcomes	Health Status		
		Hospitalisations		
		Morbidity	Co-morbidities	
			Diabetes-specific Intermediate	
			Diabetes-specific Long-term	
		Overweight & Obesity		
Mortality				
<i>Quality of Life</i>				





# Appendix 15 – WADoH Diabetes Model of Care

Diagram 2 Optimal initial and long term management of diabetes



Source: Western Australia Department of Health (2008).