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THE UNIVERSITY OF
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PhD Thesis

*Health Inequalities and the Right to Healthcare of Negev Bedouin in
Israel with Diabetes: A case study of a Marginalized Arab Indigenous
Minority*

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This thesis is submitted in partial fulfilment of the requirements for Doctor of
Philosophy degree at Warwick Medical School, University of Warwick Coventry,
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ABSTRACT

Health Inequalities and the Right to Healthcare of Negev Bedouin in Israel with Diabetes: A case study of a Marginalized Arab Indigenous Minority

Diabetes is one of the world's most pervasive chronic diseases and there are high rates of prevalence in the Arab world and amongst indigenous peoples. It is widespread amongst older Bedouin in the Negev, who are a marginalized Arab indigenous minority in Israel.

This is a multi-method case study using non participant observation in clinic settings, analysis of medical records and semi-structured interviews in a Health Centre and Hospital Outpatient Clinic and household interviews. The fieldwork took place over eight months in 2007. Statistical analysis was done using SPSS and thematic qualitative analysis was conducted using NVIVO 7 with supplementary manual analysis.

The conceptual frameworks used are the right to health and health care approach as set out in UN Special Comment 14 in relation to the availability, accessibility, acceptability and quality of health care, as well as neo materialist, materialist and socio-behavioural explanations of health inequalities linked to lay and professional explanatory models of illness.

The findings show that there are limitations on the right to health care in terms of availability of clinics and clinic hours, accessibility in terms of distance, language, cost, and information, acceptability in terms of linguistic and cultural differences

between staff and patients and quality in terms of medical records, monitoring and appropriate context specific lifestyle advice. The issue of non-discriminatory care needs to be addressed. Explanatory models of illness used by Bedouin and health professionals differ although both reflect awareness of changing lifestyles. These models link to explanations of health inequalities. There are gender differences in how Bedouin men and women understand and live with diabetes which is related to their social status and circumstances.

Some aspects of the findings are generalisable to Bedouin in the Arab world and to indigenous peoples in relation to health care provision, health inequalities and explanatory models. However, there were specific areas of health care provision that related to the marginalized minority status and situation of this population in Israel which needs to be addressed and the rights to health and health care framework provides a potential means of monitoring improvement.

KEYWORDS: Bedouin, Arabs, Indigenous People, Diabetes, Explanatory Models, Health Inequalities, Rights to Health and Healthcare, Israel

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It has been long research journey full of moments of happiness and sadness. I am very grateful to all the people who have helped and supported me during the difficult stages.

First to whom I owe a profound debt of gratitude is Professor Gillian Lewando-Hundt for her unlimited support and understanding. Her advice and comments have been the defining hallmarks to the completion of this thesis.

My deepest gratitude is owed to Prof Margaret Thorogood and Dr Loraine Blaxter for their supervision and support at various stages. Gratitude is also due to Warwick University for granting me a partial scholarship that enabled me to undertake this research. I am also indebted to the Cohen Trust as well as the Rothschild Foundation for most generously providing financial support throughout the course my research.

I would like to thank the General Health Services who gave me permission to collect the data from the two settings and also to thank the health centre and diabetic outpatient clinic staff especially to Dr Ilana Harman. I also wish to thank all the Bedouin patients and their families who agreed to be interviewed as part of this study and were so patient.

I am grateful to the School of Health and Social Studies and the staff for their support and help. Last, but not least, I am grateful to my beloved parents for their encouragement and belief in supporting my dreams of pursuing an education though

it was against the culture at that time. Deep thanks to my sisters for their support and praise, to my nieces and nephews who told me 'you are our role model'.

ABBREVIATIONS

AAAQ	Availability, Accessibility, acceptability and Quality
ADA	American Diabetes Association
BMI	Body Mass Index
NCF	The Negev Coexistence Forum for Civil Equality
GP	General Practitioner
CHS	Clalit Health Services
Hb _{A1c}	Haemoglobin A1c
HMO	Health Maintenance Organisations
ID	Identification Card
IDF	International Diabetes Federation
WHO	World Health Organisation
UN	United Nation
CBS	Central Bureau of Statistics

GLOSSARY

Ana bahis hali mush tabi`yah	I feel not as usual
Ana ma akhabas	I am not eating mix food
Badoo	Bedouin/Nomads
Badeyah	Desert
Baklava	Arabic sweets
Beet El-elah	Family house
Eid Al-Adha	Festival of Sacrifice
Eid Al Fitr	The holiday after fating moth
Emwazan	Balance
Kulli bewaja	Pain all over the body
Mhafdyn alyah	Under control
Mfakakah	Sometimes I feel my body isn't hanging together or working properly
El-Naqba	The Catastrophe
Fellaheen	Village dwellers

Halkan	Collapsing
Madaneen	City dwellers
Maqluba	Upside-down
Mitzayqah	Tightness
Mukhtalifah	I feel my body is different
Namura	Arabic sweets
Seher	Magic
Shiq	Guest section
Sukar	Sugar
Sukary	Diabetes
`andee sukary	Having diabetes
Talfanah	Exhausted
Zyn	Good
Wallah	A swear of God
Akhabas (<i>ankhabas-plural or takhbes –noun</i>)	Not paying attention to eaten food mix
food	
Shyh (Herb)	Artemisia
Ja`deh (Herb)	Teucrium polium

Moshavim and kibbutzim (Hebrew)

Communal agricultural settlements

Mimshal Tzvai (Hebrew)

Military government

I used the ALA-LC Romanization (American Library Association-Library of Congress) method to transliterate Arabic alphabet words to Roman letters in the English from Wikipedia website. It provides guidelines that make it easier to manage and read. There are two ways to write Arabic in Roman letter. The strict way of transliteration using couple with things that the simple way did not use such as accents, underscores, and underdots. ALA-LC system is used by the British library and the North American libraries to write the bibliographic names (Wikipedia the free encyclopedia)

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DECLARATION

In accordance with the University of Warwick's guidelines on the presentation and examination of the thesis, I wish to declare that this work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree. This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by giving explicit references.

Any views expressed in the thesis are those of the author and in no way represent those of the University of Warwick.

The thesis has not been presented to any other university examination either in the United Kingdom or overseas.

I hereby give my consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

SIGNED

DATE

DEDICATION

I dedicate this thesis to the grateful memory of Salamah Abu Nadi, my late father, who passed away in September 2008. Brought up as a Bedouin, he was as proud of his origin as he was of the value systems and sense of dignity that underlined its existence and purpose. However, he was also remarkably committed to modifying Bedouin cultural and traditional practices that constrained the progress, freedom and advancement of women and women's rights. It is this passion of his that has continued to inspire me. In this light, I would also like to dedicate this thesis to all Bedouin women – especially my mother and sisters – who by virtue of the cultural settings that define them, are generally unable to have what I was able to: an education.

Introduction

The study

The primary aim of this study is to extend understandings of the problem of diabetes amongst Bedouin people in the Negev region, Israel, within the wider context of Bedouin in the Middle East as a marginalised group and indigenous people in other countries worldwide. This thesis explores the beliefs, understandings, and daily self-management of diabetes, through an analysis of the interface and interplay of culture, lifestyle and gender in the Bedouin community. It also explores the practices and perspectives of the primary and the secondary health care professionals and focuses on health inequalities and rights to health.

There are two main reasons why I chose this topic. First, my mother was diagnosed with diabetes when I was child. I remember she came back one day with needles, tiny syringes and ampoules containing liquid medication. She had not told me anything and I was so curious about these new things especially when she hid them from us. I could not stop my curiosity especially when I saw her few days later lift up her long dress, take a small needle and inject it to her tummy. I ran away and told my other sisters about what I saw. All of us ran back to make sure my mother had not died.. Then she told us this is medication because she had diabetes (*sukary*). I knew that her illness had a link to sugar, especially when my mother stopped drinking tea with us and started to drink herbal tea, but I didn't understand more than that. So I lived with diabetes in my home from childhood.

I grew up in the Bedouin community, and since early on in my life I knew my limitations and the barriers for girls , but this had not stop me dreaming of continuing my studies and after going on hunger strike, my father let me attend high school.. In high school my ambition and interest grew in relation to sciences and heath. In that stage, the dream to study at university was so far away, although the university is only 30 minutes from my tribe.

But a miracle happened; I was accepted to a nursing degree. Although I wanted to study medicine at that time any opportunity to study was gratefully received. I was the first Bedouin nurse to graduate from the university so I felt that a lot of responsibilities landed on my shoulders. I then worked as a community based nurse in the clinics providing care to my own community. I have been a community activist in many organisations on topics of health, education and women's rights and carried out much health education and promotion in my work place and in the area I lived in.

During my work, the problem of chronic diseases and the lack of preventive care to stop the complications particularly of diabetes struck me. The next step was to go back to university and study the situation. So I studied diabetes from the epidemiological viewpoint in the Health Sciences Epidemiology Department of the Faculty of Health Sciences at Ben Gurion University of the Negev and completed an MSc in Epidemiology. This lacked the perspectives of Bedouin themselves and

health professionals. So I decided to come to the University of Warwick to pursue research in this area for a PhD in Health and Social Studies.

The thesis structure

The study is organised into six chapters. The first three chapters are the literature review (Chapter 1), the setting (Chapter 2), and the methodology and methods of the study (Chapter 3). There are then two findings chapters (Chapters 4 &5) setting out an analysis of the data and addressing the first two research questions and followed by the final concluding chapter (Chapter 6) which addresses these findings and also the third research question.

Research Questions

Thus, the research questions for this study are:

- a. To what extent can a rights based approach in terms of quality, availability, accessibility and acceptability extend understandings of health and health care provision to marginalised Bedouin in the Negev, Israel who have diabetes?
- b. To what extent can the materialist and socio-behavioural explanations of health inequalities extend understandings of the experiences and management of diabetes care and of marginalised Bedouin in the Negev?

- c. How generalisable to Bedouin in the Arab world and other indigenous peoples is the situation of Negev Bedouin with diabetes in terms of health care and experiences of living with the condition?

Chapter 1

Literature Review

This chapter is a critical review of literature relevant to this thesis on the understanding, management and treatment of diabetes amongst the Negev Bedouin as a case study of health and health care of a marginalized minority in Israel. The Negev Bedouin form part of the Palestinian Arab minority in Israel and as Bedouin are part of a larger minority in terms of lifestyle and culture within the Arab world. The first section focuses on the epidemiology of diabetes and obesity worldwide, amongst indigenous people, in the Arab world and amongst the Bedouin in the Negev. The second section discusses the different explanations of health inequalities and their relevance as a framework for examining the situation of indigenous people, Bedouin in the Arab world and the Negev Bedouin. The third section examines the literature on a rights based approach to health as a conceptual framework for the analysis of health care to a marginalized minority. The fourth section examines health intervention programmes and approaches to tackling diabetes amongst indigenous and minority peoples. Finally the research questions and conceptual framework of the thesis will be set out.

Diabetes Worldwide

Industrialisation and modernisation have brought many benefits to humanity including the discovery of treatments and vaccines for many infectious diseases.

However there has been an increase of non-communicable diseases, such as cardiovascular diseases, diabetes, and strokes as a result of modern lifestyles, which have come with reduced physical activity and increased food consumption. 80% of deaths worldwide attributable to chronic diseases occur in developing countries (WHO 2005).

In the last few decades there has been dramatic health transition in the demography and epidemiology of the developing countries. The improvement of preventive and curative maternal and child health care and improved accessibility of care has resulted in a reduction of birth rates, infant mortality rates and increases in life expectancy (Escovitz 1992, Fuster and Kelly, 2010). There are a growing number of middle-aged and elderly persons with an increase of non-communicable diseases (WHO 2011, Fuster and Kelly 2010). There has been a considerable increase in the rates of diabetes in the world, and a dramatic increase amongst minority groups and indigenous and first nation people's such as aboriginal people in Australia (Wang and Hoy 2004) and Canada (Bisset, Cargo et al. 2004). This increased incidence is related to their marginalised status, poverty and the rapid changes in their lifestyles within the countries they live in. There has also been a rapid increase in diabetes amongst Arabs in the Middle East and also within this region amongst Bedouin. My research will analyse and extend understandings of the management of diabetes amongst an indigenous marginalized minority population, the Negev Bedouin, and health professionals working with the Bedouin in the Negev in Israel.

Indigenous People

The UN's Working Group formulated a definition of indigenous people in 2004 which is commonly used as an internationally accepted working definition,

“Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing on those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions and legal system.

This historical continuity may consist of the continuation, for an extended period reaching into the present of one or more of the following factors:

Occupation of ancestral lands, or at least of part of them;

Common ancestry with the original occupants of these lands;

Culture in general, or in specific manifestations (such as religion, living under a tribal system, membership of an indigenous community, dress, means of livelihood, lifestyle, etc.);

Language (whether used as the only language, as mother-tongue, as the habitual means of communication at home or in the family, or as the main, preferred, habitual, general or normal language);

Residence on certain parts of the country, or in certain regions of the world;

Other relevant factors” (UN 2004:2)

This thesis will present the argument that the Bedouin in the Negev are an indigenous people living as a disadvantaged minority within Israel, displaced from their ancestral lands which are now owned by the Israeli state, sharing a culture, language and group identification. The thesis will be a case study of a more general problem of diabetes and its management amongst Bedouin as a marginalised minority and an indigenous people. Since there is a high rate of diabetes in the Arab world more generally, it will also consider how Negev Bedouin health and health care in relation to diabetes is similar or different from the rest of the Arab world and more specifically to the situation of Bedouin in other countries in the Arab world.

Epidemiology of diabetes

This section examines the epidemiology of diabetes and obesity internationally, amongst indigenous people, in the Arab world and amongst the Bedouin in the Negev, Israel.

In 2003, it was estimated that there were at least 171 million people worldwide with diabetes the majority of whom were living in developing countries (Wild, Roglic et al. 2004). The WHO estimated that the prevalence of diabetes in the Arab world is expected to rise substantially by 2030 (WHO, accessed 20/07/2011).

Diabetes is considered to be one of the main burdens of disease in the world, not only because of the enormous number of people living with it, but also because of

the high rates of morbidity and mortality that occur as a result of secondary diabetes and its associated complications. Complications of diabetes occur when the level of glucose in the blood exceeds manageable levels. The normal concentration of glucose in fasting blood plasma is up to 7.0 mmol l⁻¹ (126 mg dl⁻¹) and for whole blood 6.1 mmol l⁻¹ (110 mg dl⁻¹) according to classifications by the WHO (WHO 2006). Diabetes medications aim to keep glucose levels in the blood within the normal ranges 3.3-6.7 mmol l⁻¹ (60-120 mg dl⁻¹) and to prevent diabetes associated complications.

Researchers have predicted significant increases in the number of people with diabetes in coming years and have discussed the impending global diabetes burden and its implications (Amos, McCarty et al. 1997; King, Aubert et al. 1998 ; Zimmet, Alberti et al. 2001 ; Wild, Roglic et al. 2004). Whilst the phenomenon is a global one, there is a trend for developing countries and certain ethnic minority groups within these countries to be at a greater risk. King et al, (1998) compared the differences between the prevalence of diabetes in developed and developing countries in 1995, and identified two major trends. Firstly, the age structure of diabetic people differs between developed and developing countries. In developed countries the majority of people with diabetes were 65 years or older, whilst in developing countries the bulk of people with diabetes fell between the 45-64 age groups. The researchers predicted that this trend of differences in age structure between developing and developed countries will continue up to 2025. Secondly, the two main modifiable risk factors contributing to the increased incidence of diabetes are reduced physical activity and the increased consumption of energy rich foods

which lead to obesity. Both factors are connected to the changes in indigenous peoples' lifestyles globally.

The total number of people worldwide with type 2 diabetes was expected to increase from 171 million in 2000 to 366 million in 2030 (Wild, Roglic et al. 2004).

However, the prevalence had already reached 371 by 2012 and the predictions are that prevalence of diabetes on a global scale may reach 530 million people in 2030 (Badran and Laher 2012).

Diabetes amongst indigenous people

Indigenous people around the world suffer from higher incidences of diabetes.

According to Smith-Morris (2004) more than half of the adult Pima Indians, both men and women, have diabetes and the prevalence of the disease has increased dramatically in the last three decades. Transformations to the Pima Indians' ways of living, such as a trend towards waged labour and away from farming for example, have resulted in reduced levels of physical activity amongst the population. The need for alternative sources of food has led to a subsequent reliance on government commodities and other processed food. This has exposed them to high energy, fatty and sweet food and drink, which have caused a rise in the intake of calories, and thus to increasing obesity.

According to Daniel (1999) the prevalence of type 2 diabetes amongst the indigenous population of Australian aborigines is 15–25% compared to 2–5% for the non-aboriginal population in Australia. In addition there was a linear trend where the greater incidence was associated with greater Body Mass Index (BMI). Another

study of Australian aborigines reported increasing levels of BMI, but in contrast, also reported a fall in the prevalence of impaired glucose tolerance (IGT) and unchanging diabetes prevalence (Rowley, Gault et al. 2000) . These results could be due to the intervention programme that was running to address the chronic health problems related to changing lifestyles. Similarly, the prevalence of diabetes in aboriginal First Nation peoples in Canada is three to five times higher than the non-aboriginal communities (Barton, Anderson et al. 2005).

Diabetes in the Arab world

The prevalence of type 2 diabetes has increased dramatically in the Arab countries in the Middle East and North Africa (see Map 1), over the last three decades.

According to International Diabetes Federation (2010), six Arab countries are at the top of the list of diabetes prevalence: these countries are Kuwait, Lebanon, Qatar, Saudi Arabia, Bahrain, and United Arab Emirates (UAE). The estimation is 10.9% of Arab population have diabetes (Badran and Laher (2012). In 2011 there were 32.8 million people with diabetes which projected to increase to 60 million in 2030 (IDF 2010). This rapid increase in diabetes is owing to wealth generated by oil-rich resources in Gulf countries which has led to rapidly improved living standards and to industrial development, accelerated urbanization, drastic changes in nutrition, reduced physical activity, and a greater reliance on mechanization. (Badran and Laher, 2012).

Figure 1.1: Arab countries map



Source: <http://www.arabbay.com/arabmap.htm> accessed on 25/07/2011

Table 1.1 shows the numbers of people with diabetes in 2000 and the projected increase by 2030. This increase reflects the aging population and the increase in diabetes as a non- communicable disease in the region.

Table 4.1: Numbers of people with diabetes in 2000 and projected numbers by 2030

Country	2000	2030
Bahrain	37,000	99,000
Egypt	2,623,000	6,726,000
Iraq	668,000	2,009,000
Jordan	195,000	680,000

Country	2000	2030
Kuwait	104,000	319,000
Lebanon	146,000	378,000
Libyan Arab Jamahiriya	88,000	245,000
Morocco	427,000	1,138,000
Oman	113,000	343,000
Qatar	38,000	88,000
Saudi Arabia	890,000	2,523,000
Sudan	447,000	1,277,000
Syrian Arab Republic	627,000	2,313,000
Tunisia	166,000	388,000
United Arab Emirates	350,000	684,000
Yemen	327,000	1,286,000
Total	15,188,000	42,600,000

WHO 'Country and regional data, Prevalence of diabetes in the Eastern Mediterranean Region' Source: WHO website accessed 20/07/2011

Table 1.2: Prevalence of type 2 diabetes in Arab countries, The data are separated for males and females aged between 20–79 years, using IDF estimates for 2011. Population numbers are taken from the CIA World Factbook 2008. (Badran and Laher 2012)

Country	Population (×1,000)	Comparative* diabetes prevalence (%)	Male (×1000)	Female (×1000)
Kuwait	1,868	21.2	175.3	122.6
Lebanon	2,788	20.1	230.9	296.9
Qatar	1,541	20.1	166.2	50.6
Saudi Arabia	17,023	20.0	1,450.7	1,308.8
Bahrain	986	19.8	91.4	59.3
UAE	6,107	19.2	296.2	128.9
Egypt	48,305	16.9	3,123.7	4,199.5
Libya	3,875	14.1	211.2	225.1
Jordan	3,268	12.3	148.8	142.7
Oman	1,810	10.7	88.1	50.3
Syria	10,824	10.1	437.1	452.3
Yemen	10,902	9.8	366.1	361.1
Tunisia	7,084	9.6	278.3	351.2
Iraq	15,068	9.3	459.1	629.9
Sudan	22,000	8.7	947.9	718.7
Algeria	22,619	7.0	704.4	730.7
Morocco	19,964	6.9	608.7	659.1
Djibouti	480.9	6.4	13.1	13.1
Mauritania	1,756	4.3	29.1	31.4
Somalia	4,275	4.2	87.6	97.4
Israel	4,707	7.6	206.2	194.1

**All comparisons should be done using the comparative prevalence, which is adjusted to the world population. Israel has been added to this table to provide a comparison but is a mixed population of Arab and Jews*

The difference in diabetes prevalence in Arab societies emphasises the heterogeneity of both the environmental situation and genetic factors (Jaber, Brown et al. 2003). In Bahrain as in other studies of diabetes in the Arab world, women have a higher rate of diabetes than men, the incidence of diabetes increases amongst higher age groups,

and the peak prevalence is in the 50-64 years age group. Some studies reported low estimations of prevalence in Arab countries such as 0.19% in Benghazi-Libya (Kadiki and Roaed 1999) and other over estimation such as 35% in Bahrain (Jaber, Brown et al. 2003). However, the latest update from International Diabetes Federation (IDF) (see Table 1.2) reported that overall the prevalence of diabetes is high in Arab countries, and six of the Arab countries lead the world with the highest prevalence of diabetes.

It should be borne in mind that 60% of patients with diabetes were obese in Benghazi (Kadiki and Roaed 1999). Furthermore the study conducted in the Benghazi area did not provide clear information regarding who collected the data, nor where and how the data were collected. It was not clear if the Benghazi region was an urban or rural area or both, nor was there information about the quality and accessibility of the health services for the population.

In Oman, the results of a national survey which aimed to estimate the prevalence of diabetes showed an increase from 12% in 1991 to 16% in 2002 (Al-Lawati, Mohammed et al. 2003). The UAE study presented a high crude prevalence of diabetes 20% which was significantly higher among men than women. However after age-adjustment was considered, the prevalence was higher in woman (Malik, Bakir et al. 2005). The overall prevalence of diabetes mellitus was found to be 10% in men and 7% in women in a study in Saudi Arabia and the researchers found that obesity was present in 13% of the men and 20% of the women (Warsy and El-Hazmi 1999).

In the case of the Negev Bedouin prior to 1960, diabetes and obesity, were largely unknown in the Bedouin population (Ben-Assa, 1964). They have now become major public health problems (Ben-Assa 1964; Weitzman, Lehman et al. 1974; Abu-Rabiah and Weitzman 2002). According to Abu-Rabiah and Weitzman (2002) the prevalence of diabetes amongst Bedouin is twice the prevalence of that previously reported among Jews in Beer-Sheva in a nationwide survey (Al-Krenawi 1999). Cohen et al (2005) reported the age-adjusted prevalence of diabetes amongst Bedouin was 5.3% and 3.7% in the non-Bedouin in the Negev.

Obesity

Obesity is becoming a serious health problem worldwide. It affects both men and women of all ages and in particular minority groups, indigenous peoples and people adopting a more sedentary affluent lifestyle. The definition of obesity according to the World Health Organisation (WHO) is being equal or more than 30 kg/m² of Body Mass Index (BMI) while overweight is defined as a BMI 25-29 (World Health Organisation 2006). Central obesity is defined as waist circumference (WC) over 95 cm for women, 100 cm for men, and/or WHR of > 0.85 in women and > 0.95 in men (Abolfotouh, Daffallah et al. 2001).

As a result of urbanisation, the prevalence of obesity has increased worldwide. This rapid change gives obesity the status of an epidemic. Fifty-eight percent of adults are obese or overweight in many countries (Astrup and Finer 2000). Being overweight or obese is associated with Impaired Glucose Tolerance (IGT) and diabetes type 2.

Obesity amongst indigenous people

The observed increase in obesity has been related to changing lifestyles in terms of diet, physical activity, and other behaviour patterns such as smoking and alcohol consumption. There are also issues of genetic susceptibility to obesity as well as the co-morbidity that accompanies obesity.

Leonard et al (2002) conducted a survey amongst nine communities of Torres Strait Islander people (a mix of Australian aboriginal people and native Torres Strait Islander people) aged 15 and above, between 1993-1997. They reported that 80% of native Torres Strait Islander people who participated in the study were overweight or obese. Similarly, McDermott et al (2000) found that the prevalence of obesity increased significantly by 60% during an eight-year survey carried out amongst a rural Aboriginal community in central Australia from 1987 to 1995. They also found that the prevalence of diabetes increased by 80% during this period.

Lako and Nguyen (2001) conducted a study amongst urban indigenous women in Fiji to observe the association between the diet and potential risk factors for diabetes. Two hundred Fijian women aged 30-39 years of age participated. The results showed that 79% of the subjects were overweight or obese with a mean BMI of 31 kg/m², which had increased from kg/m² as found in previous studies in the last 20 years. 77% of subjects had central obesity.

Two examples in particular highlight changes to diet intake amongst indigenous peoples around the world, that of the Navajo and Pima Indians. The diet of the Navajo people has changed since their first contact with European people when they

arrived in America. The early period diet relied on stone-ground corn and wild seeds containing high levels of fibre, complex carbohydrates and low levels of simple sugars and fats. By the 1940s, the diet components had largely changed, so that wheat flour replaced cornmeal, whilst wild seeds and fruit were rarely gathered, and sugary foods like sweets became commonly available (Wolfe 1993).

Another significant example of the changes occurring amongst indigenous peoples is the changing diet of the Pima Indians. In the past, the Pima Indian food supply was dependent on hunting and gathering. Later, in the 18th and 19th centuries, the diet changed to food cultivated by farming, such as wheat, and corn. They stopped eating their traditional bread made from corn and began eating fried wheat tortillas (Smith, Manahan et al. 1993).

At the same time as these dietary changes were occurring, the process of displacement modernisation and urbanisation meant that many indigenous peoples were losing access to their natural resources and land, and were moving to reservations or settlements where the level of physical activity expended in their daily life decreased. With the two factors working in combination - a diet containing high levels of fats and sugar and reduced physical activity - levels of obesity and overweightness increased rapidly. Similar dynamics have been observed amongst different indigenous peoples such as the Pima Indians at Gila River (Williams, Knowler et al. 2001) and the aboriginal people of Sandy Lake, northwest Ontario (Wolever, Hamad et al. 1997).

Obesity amongst Arab populations

In many Arab countries where oil has been the predominant mainstay of the economy, rapid urbanisation and industrialization has ensued, so that many Arabs, particularly those living in cities, have abandoned their traditional lifestyles and adopted many aspects of a ‘Western’ lifestyle, such as a diets which are richer in saturated fats, refined foods and sugar. They also eat greater quantities of food (Abu-Saad, Weitzman et al. 2001; Ahmed 2003). Food is part of the custom of hospitality amongst Arabs in general, and the sharing of food is central to social gatherings of family members and neighbours.

Table 1.3: The prevalence of obesity in the Arab world, The data are separated for males and females aged between 15 and 100 years, using WHO estimates for 2010.(Badran and Laher 2011)

Country	Male	Female
Kuwait	30%	55%
Lebanon	15%	27%
Qatar	19%	32%
Saudi Arabia	23%	36%
Bahrain	21%	38%
UAE	25%	42%
Egypt	22%	48%
Libya	12%	25%
Jordan	20%	38%
Oman	8%	17%
Syria	12%	25%
Yemen	2%	2%
Tunisia	8%	33%
Iraq	8%	19%
Sudan	2%	7%
Algeria	6%	16%
Morocco	4%	23%
Mauritania	5%	27%
Somalia	1%	3%
Israel	18%	26%

** Israel has been added to this table to provide a comparison but the figure is a mixed population of Arabs and Jews.*

According to WHO (2010) Kuwaiti women had the highest obesity prevalence rate amongst Arabs (55%) and were ninth in the world rankings. Moreover 30% of men in Kuwait were obese which placed them also as the highest in Arab world, followed by men in the UAE (25%) and Saudi Arabia (23%). In terms of the obesity prevalence rates of women, the second place was held by Egypt (48%) and the third highest were women in the UAE (42%).

According to Al- Mahroos and Al- Roomi, 15% -20% of people in Bahrain are obese, with 60% of men and 70% of women aged 50-59 being overweight or obesity (Al-Mahroos and Al-Roomi, 2001). The researchers related the high prevalence of obesity and overweightness to the process of modernisation, increased food consumption and lack of physical activity. In Israel, data from a recent study in the centre of the country (Hadera district) has shown that the coronary heart disease mortality rate of Arab men was 1.6 times higher than Jewish men while the diabetes mortality rate was 2.3 times higher in Arab men compare to Jewish men. The differences were even bigger amongst women, with the coronary heart disease mortality rate of Arab women as 2.4 times higher than that of Jewish women and the diabetes mortality rate of Arab women was 3.4 times higher than Jewish women (Abu-Saad et al. 2012). These differences were linked to dietary differences and ethnic disparities in socio-economic status amongst older people.

An Omani study reported the prevalence of 21% of a metabolic syndrome (Al-Lawati et al. 2003). The metabolic syndrome is characterized by a group of metabolic risks that include central obesity, blood fat disorders, insulin resistance or glucose intolerance and raised blood pressure. Several studies carried out in Arab

societies have illustrated that obesity is less common in rural areas compared with urban areas. Herman et al (1997) for example, conducted a study in Egypt amongst persons aged 20 and above from rural agricultural villages in Kaliubia, and in an urban metropolitan area of Cairo. As well as finding that obesity was less common in rural areas than in urban areas, the researchers also found that obesity was less common amongst men of low socioeconomic status compared with men of higher socioeconomic status. On the other hand, obesity was common amongst women of both high and low socio-economic status. This was probably due to differences in levels of physical activity and diet.

A 5-year national epidemiological health survey (1995-2000) was conducted in Saudi Arabia to assess the prevalence of diabetes mellitus (DM) applying the new criteria for defining DM agreed by the World Health Organisation and American Diabetes Association (WHO/ADA DM). The study involved participants aged between 30 and 70 from both rural and urban areas. The study aimed to recruit a sample size of 20,000 subjects. The estimated prevalence of diabetes mellitus was 23%, whilst the prevalence of obesity was 35.6%. It also demonstrated that amongst women with central obesity, diabetes was double that of women with a smaller waist circumference, whereas only 40% of men with central obesity had diabetes (Al-Nozha et al. 2004).

A recent study in Israel compares the differences in rates of CHD and diabetes affect between Arabs and Jews in Israel (Abu-Saad et al. 2012). This cross –sectional study of the population in Hadera district in the centre of the country is mixed and in addition to the ethnic differences in diet, and socio-economic disparities, there were

differences in the rates of coronary heart disease (CHD) and diabetes between the Jews and Arabs. Arab men were 1.6 times more likely to have CHD and 2.3 times more likely to have diabetes than Jewish men and Arab women were 2.4 times more likely to have CHD and 3.4 times more likely to have diabetes. The Bedouin in the Negev also are part of the Arab population and fit into this general epidemiological picture perhaps with higher rates of diabetes.

This case study of Negev Bedouin Arab men and women is an example of a marginalized socially disadvantaged minority group who are experiencing a rapid rise in the prevalence of diabetes and as such is similar to other groups in the Arab world.

Explanations of the rise in diabetes

In 1962 James Neel proposed the “thrifty genotype” theory to explain the high prevalence of diabetes amongst indigenous people. He suggested that diabetes is genetically determined but environmentally triggered, and was an evolutionary adaptation to a hunter gatherer lifestyle when food supplies were intermittent. The adaptation allowed quick insulin specific responses to either feast or famine events, which minimised renal loss of glucose (Neel 1962). Neel’s theory however is difficult to prove historically, and nowadays, diabetes is more commonly thought of as a polygenic disease, where different genes grant susceptibility to different communities (King and Roglic 1999).

Neel developed his theory when no distinction was made between type 1 and 2 diabetes. Thus while his theory is applicable to type 2 diabetes, of which obesity, is a

major factor for susceptibility, his theory fails to explain the prevalence of type 1 diabetes. Another criticism of his theory which arose following more information being gathered about diabetes in developing countries, is that diabetes was shown to occur in the same frequency among adults in these countries as among the ethnic groups which were classed under the criteria of the thrifty genotype (King and Roglic 1999).

In addition, a study conducted by King and Roglic examining the archaeological evidence for Neel's theory among the North American Indians concluded that diabetes susceptibility could be accounted for through food preference rather than through Neel's theory (King and Roglic 1999). Along this vein, Reaven (1998) stated that the main issue to develop type 2 diabetes is the insulin muscle resistance, whilst Ozanne and Hales (1998) come to the same conclusion in their article, thus challenging the validity of the thrifty genotype theory.

Hales and Barker's (1992) revised theory about the thrifty phenotype challenged Neel's theory. In their cohort study of the Nauruans people in the Pacific, they noticed that low birth weight was associated with type 2 diabetes. This community suffered from malnutrition during the Second World War but had later become affluent. The phenotype hypothesis suggested that fetal and infant conditions determine the possibility to have diabetes later on in life. They reported a recent decline in the prevalence of diabetes which they attributed to the improvement in nutrition status during fetal and infant periods (Hales and Barker 1992).

There is no absolute evidence regarding the locus of the allele which leads to diabetes. According to research by Southam et al (2009) there was no evidence of overrepresentation of the allele's frequencies in the susceptibility loci of type 2 diabetes or obesity in the genetic tests, which again contradicts Neel's theory. Other research has found evidence for actions of alleles in single or multi loci, which might suggest certain alleles might explain family clusters (Khamaisi and Raz 2002), but there was no significant evidence concerning genetics and these changes in the alleles with diabetes.

However, the prominence of the Neel's theory has dwindled with the emergence of other theories which place more emphasis on environmental factors such as recent socioeconomic - industrial developments which influence people's eating habits and their physical activities. The rise in the frequency of obesity, glucose intolerance and insulin resistance, along with associated hypertension and hyperlipidaemia, which follows such post-industrialized environments, has led some to predict that the number of people with diabetes will reach 350 million by 2030 (Wild, Roglic et al. 2004).

Today as more information is gathered regarding diabetes, it is possible to see that it is spreading globally with many communities experiencing high rates of the disease. As such, rather than using European communities as a 'normal' benchmark, and other communities as 'unusual', it has been suggested that it might be more useful to research why European populations have lower than usual rates of diabetes, and consider European populations the 'unusual' position (Swinburn 1996).

The Negev Bedouin have a high prevalence of diabetes (Abu-Rabiah and Weitzman 2002; Cohen, Gefen et al. 2005) and they have experienced a socioeconomic transition towards affluence along with more food and a sedentary lifestyle. All these factors play important roles with regards diabetes (Khamaisi and Raz 2002).

In addition, another factor relevant more widely to Arab societies is that women's lives are highly socially determined due to the cultural and social restrictions imposed on them, both in terms of physical and social freedom of movement.

Lay beliefs concerning diabetes

Every social group has particular beliefs and conceptions regarding health and illness. A knowledge and understanding of any specific lay belief system is therefore essential to develop suitable educational and preventative health programmes.

Knowledge about health beliefs can help health services providers to understand the way a group of people may think about health and illness in general and diabetes in particular.

It is common for lay people to often view health and illness differently from health professionals even if both come from the same cultural background (Helman 2001).

The way people talk about health and illness is grounded deeply in their social and cultural context and it reflects the experiences and the knowledge which has been passed through generations in dealing with illness. Health professionals have learnt scientific theories about disease and have authoritative knowledge whilst, patients have experiential knowledge of illness

Patients' experiences with diabetes are varied. How patients decide to live with their conditions depends on many factors including personality, knowledge, socio-economic situation and their level of education. In 'coming to terms with diabetes', Kelleher (1995) has recognised people have three types of strategies when living with diabetes. The distinction between these groups depends on two conditions: the degree to which they follow medical advice and the extent to which they apply it to their life without limiting their daily activities. The first group was the copers, the second was the adapting or normalising group, and the third was the worriers.

Arcury et al (2005), showed that people with low incomes from rural areas of North Carolina, had an unclear understanding of diabetes. The participants who did not have diabetes, believed diabetes could be a hereditary condition. They also thought that strong emotions, negative or positive, could cause diabetes. The participants disagreed about the lifestyle factors that cause diabetes. There was a lack of clarity concerning the causes of diabetes but it was known that people with diabetes changed their diet after having diabetes. Exercise was not recognized as having a causal relationship with diabetes.

Arcury et al (2004), argued that people with a high risk of diabetes such as indigenous peoples, had the least access to care and were the least able to manage their condition. When health services were not accessible, people tended to rely more on folk medicine and traditional remedies. The symptoms of diabetes and the chronic sequelae participants described were usually what they had observed in their family members and friends. For instance, they mentioned amputations, fatigue and dialysis rather than the symptoms that appear with diabetes such as thirst, frequent

urination and vision problems (Arcury, Skelly et al. 2005). Although this study was done in the rural USA, its findings have some relevance to the findings in this study.

The ground breaking work of Arthur Kleinman (2006) in relation to explanatory models of illness is of relevance to this study. Kleinman argued that both patients and health professionals have explanatory models of why and how illnesses happen and that adherence to treatment is increased if the health professionals understand the patients' explanatory models. In this study, the explanatory models of patients and health professionals are different and link in some ways to explanations of health inequalities.

Diabetic patients have their own explanatory models regarding the onset, causes, treatment and management of diabetes and these differ from the health professionals and this has been shown in different studies (Ferzacca 2012, Luyar, 1991).

Lay epidemiology is a term used for when health risks are interpreted by ordinary people (Allmark and Tod, 2005) using their explanatory models. Some researchers (Davison et al 1991) working in the area of prevention of coronary heart disease have argued that the prevention of chronic disease might be tackled through the public approaches of behavioural change that build on lay epidemiology. In the case of It has also been argued that sometimes there is an overestimation of the impact of official policies and underestimation of peoples' models of health and illness (Bury, 1994). Blaxter (1997) in her research on women in Aberdeen argued that differences in the way people think about what causes health and illness was linked to inequalities in health so that those who were more socially disadvantaged

attributed illness to external causes rather than seeing them as within their own control.

Lay beliefs about diabetes and its treatment are grounded deeply in the cultural context. People understand diseases through a reliance on their social understanding and religious beliefs. The treatment of diabetes is sometimes done by using both folk and prescribed biomedicines. According to Moss and McDowell (2005) rural Vincentians in the Caribbean use folk and herbal remedies and this was strongly linked to their religious beliefs and cultural identity. The participants ascribed the success in dealing with diabetes to herbal remedies, rather than, prescribed medicine. Moss and McDowell (2005) found participants used prescribed medicines and herbs simultaneously. In this thesis, the lay beliefs of Bedouin with diabetes were relevant to their understandings of their condition and how they lived with it and will be explored in Chapter 5.

Explanations of health inequalities

For a comprehensive understanding of the health status of the Negev Bedouin, it is essential to review the patterns of health inequalities within Israel. There are several explanations for health inequalities and some of these are relevant to the situation of the Negev Bedouin who are the most socially disadvantaged group in Israel.

The Black Report (1980) discussed the main explanations for health inequalities, which were the statistical artefact explanation, theories of natural or social selection, materialist approaches and socio-behavioural explanations (Townsend, Davidson et al. 1998; Shaw, Dorling et al. 1999).

The artefact explanation argued that the health inequalities demonstrated by statistics were a numerical artefact. For example, the numbers of people in unskilled labour today may be far fewer than in the past, and therefore, although their health is the worst, in actual numbers this refers to fewer people than in the past. However, evidence from longitudinal cohort studies and life course analysis has demonstrated clearly that inequalities in health are not statistical artefacts (Townsend, Davidson et al. 1998). If one applies this explanation to the Negev Bedouin, one would argue that in the past, infant mortality was under-recorded owing to home births and deaths so that the decrease in infant mortality during the last forty years has been better than the statistics demonstrate. However, today 99% of births take place in the hospital and even in the 1980s this figure was over 95% (Forman 1995). Therefore for the last thirty years, the recorded birth rates and infant mortality rates have been accurate. Although there has been a decrease in infant mortality amongst the Bedouin, this type of explanation cannot explain the huge difference between the infant mortality rates of Jews and Bedouin Arabs in the Negev in Israel.

Socio-behavioural explanations view health inequalities as a result of people's behaviours and choices. It is argued that people are responsible for their diet, lack of exercise and smoking (Shaw, Dorling et al. 1999; Carlisle 2001). This explanation tends to be favoured by health professionals. Amongst the Negev Bedouin, many health professionals consider that Bedouin have high rates of diabetes owing to a diet heavy in sugar and lipid fats and a lack of exercise. However, the socio-cultural environment prevents women exercising and there are other factors such as the lack of transport to outlets of fresh fruit, along with a lack of availability of fresh

food in nearby stores, thus an explanation that focuses on individuals does not take these social factors into account (Abu-Saad et al 2009, Weitzman et al. 1974).

Psycho-social explanations focus on stressful conditions in people's lives and how these affect their behaviour by increasing their vulnerability to mental health problems and physical illness (Townsend, Davidson et al. 1998). According to Marmot and Wilkinson (2006), there are two levels where social determinants impact on health inequalities. The first is through the individual level as the experiences and awareness a person develops in an unequal society results in stress and poor health. The second is at the community level, where widening the gap between individuals leads to weaknesses in the community structure such as education and social programmes. Therefore psycho-social aspects may be the secondary results of an unequal distribution of material resources in a given society and thus show that psychological effects can weaken social determinants of health (Marmot and Wilkinson 2006; Wilkinson and Pickett 2010).

A materialist explanation on the other hand views health inequalities as being due to differences in material circumstances such as the working environment and housing conditions. Studies show that poor areas tend to have higher risks of fire and accidents (Broides 2003). Housing in these areas have high concentrations of people, which register high rates of asthma and respiratory infections, especially amongst children (Peled et al. 2006; Ben-Shimol et al. 2010). An example of the materialist explanation applied to the Negev Bedouin would be that the high rates of gastro-enteritis(Givon-Lavi et al. 2008) and stunting in growth among young children, is

linked to living in poor housing conditions in shanty towns without running water (Forman 1995).

Neo materialist explanations focus on the distribution of resources in the community as a result of government policies. The theory does not focus on the particular household conditions in the way a materialist explanation might. Rather it focuses on taxation, service provision, rights to education and health care within a population. In relation to the Negev Bedouin, Israeli state policies invest less in the Bedouin community, and there are wider gaps between Bedouin education, health care, infrastructure, planning and development compared with other parts of Israel. The state refrains from recognising 45 Bedouin villages, which has resulted in depriving Bedouin from services and equal opportunities. A poor provision of quality education for the Arab minorities has meant that the bulk of employment opportunities available to Bedouin are limited to skilled and unskilled manual labour although some Bedouin work in the professions as teachers, lawyers, doctors and nurses or are entrepreneurs, labour contractors or truck drivers.

This thesis will mainly focus on materialist, neo materialist and socio-behavioural explanations, as frameworks to understand and explain health inequalities in relation to health status and views of Bedouin with diabetes about living with their condition. Another conceptual framework for analysis of health care provision is a rights based approach.

Right to Health

In recent years the right to health has become a framework for monitoring access to health and healthcare. The right to health is one of the fundamental human rights that have been enshrined in international and regional human rights treaties as well as national constitutions. In the Universal Declaration of Human Rights (1948) “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control” (UN, 1948). Subsequently the International Covenant of Economic, Social and Cultural Rights (UN, 1966) stated that the states should recognise the right of everyone to receive the highest achievable standard of physical and mental health, which included preventive, curative and palliative health care (UN, 1966). General Comment 14 was issued by the United Nation Committee on Economics Social and Cultural Rights, to further elaborate the right to health (UN, 2000). General Comment 14 explains comprehensively the right to the health and the responsibilities of the state to respect protect and fulfil these rights. It not only set out the right of access to health services but also to insurance from the fundamental factors effecting health. It also emphasizes individual and collective rights to health and how they are anchored in international law (Stuttaford 2004).

It emphasizes the entitlements which include the right to protected health system which provides equality of opportunity for people to enjoy the highest attainable level of health care (UN, 2000). The right to health was traditionally seen as a legal

issue; however it is it is a conceptual framework being used by legal scholars, human geographers and social scientists when debating civil and political rights.

Sites for health rights (Stuttaford et al 2009) refer to where the right to health is invoked, protected or violated, and it can also include individual and collective rights. In these sites such as schools, clinics, traditional healers, and food markets goods and services should be provided that are available, affordable, acceptable, non-discriminatory and of sufficient quality (General Comment 14, 2000)

In many developing countries the economies are controlled by clans, tribes or families with collective rights and obligations. The western individual rights approach was introduced when they were undergoing fundamental changes in the industrial economy and the relations between people and the state became more regulated and protection developed (Odgaard et al. 1998).

The individual and collective rights to health sometimes contrast with each other. For example, the case of disease control, involves social and cultural concerns as well as complex medical and public health ethics. Medical ethics traditionally focus on the physician-patient relations, such as informed consent, confidentiality, privacy and dignity. Public health ethics focus on populations and the protection and promotion of health in communities (Verma et al. 2004).

The elements of the right to health include availability, acceptability, accessibility and quality (AAAQ). Firstly, the availability highlights the health care facilities, goods and services including the underlying determinants of health such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and

trained staff. It also includes developing preventive, plans and programs health by the state.

The second component is accessibility that stress that the health facilities and services should be accessible to everyone without discrimination, under the control of the State party. It includes four overlapping parts: Non-discrimination, Physical accessibility, Economic accessibility and Economic accessibility of the facilities, goods and services.

Thirdly, the acceptability which means that all health facilities, goods and services must respect culture of individuals, minorities, peoples and communities, sensitive to gender issues.. Finally, health facilities, goods and services must be scientifically and medically appropriate and of good quality with skilled health professionals and appropriate equipment (UN 2000).

It is of note that within General Comment 14 (UN 2000) that in addition to the emphasis on the right to available, accessible and acceptable health care, there is a special section on the rights to health of indigenous people and minorities. It is therefore of particular relevance to this thesis and provides a conceptual framework for monitoring and evaluating the availability accessibility, acceptability of health care by the State. This case study therefore will utilise this conceptual framework and will apply it and extend to the situation of Negev Bedouin in Israel as a minority and an indigenous peoples and also to the situation of Bedouin more widely in the Middle East whose lifestyle and social conditions mean that they could be considered a marginal minority.

The right to health as a framework for examining the AAAQ of health care provision to Bedouin has been used in a study of Bedouin in Jordan (Hundt-Lewando et al 2012) which showed that there were issues of accessibility and acceptability. Similarly research in Lebanon (Chatty 2011) showed similar problems although without using this framework. This thesis will utilise this framework to extend understandings of the rights to health care of Bedouin with diabetes in the Negev.

Community based lifestyle interventions

Several community interventions carried out amongst indigenous people are relevant to the Bedouin case. The aims of the interventions were varied and included prevention, treatment and attempts to understand the situation thoroughly in specific communities. These studies are also helpful in that they could shed light in planning future community interventions for the Bedouin community.

Results from intervention trials have shown that losing weight and exercising yields significant improvement in controlling diabetes (Narayan, Hoskin et al. 1998 ; Mau, Glanz et al. 2001; Murphy, McAuley et al. 2003; Simmons and Voyle 2003). A lifestyle intervention to prevent type 2 diabetes was carried out amongst the Maori of New Zealand. Results showed the importance of intensive monitoring of participants who have diabetes, in order to discuss their dietary issues and encourage them to take part in exercise session. Murphy et al (2003) emphasised that the programme should be local and take into account the special needs of the community. Other issues raised from this programme were the cost and the limited access to healthy food which is problematic for people who are unable to purchase

it. In order to help patients with diabetes to cope successfully with their health situation, it was recommended that health care providers should provide them with simple and sufficient information about diabetes and encourage them to make changes in their diet and physical activity (Simmons and Voyle 2003).

Change of lifestyle is crucial to the success of an intervention programme. A one year supported lifestyle intervention carried out amongst Native Hawaiians found that participants who carried out the programme advice about diet and exercise had better outcomes those than who received the standard intervention (Mau, Glanz et al. 2001). Results showed an improvement in lowering fat intake and rates of physical activity amongst the intervention group.

A study conducted amongst the Pima Indians in Arizona also found that interventions characterised as less direct and less structured were more successful in sustaining changes in physical activity and diet than intervention using structured activity and nutrition education (Narayan, Hoskin et al. 1998). Researchers stressed that the maintenance of outcomes resulting from interventions was based on taking into account the cultural and historical background of the Pima Indians.

The usefulness of community interventions has always been questioned (McDermott, Rowley et al. 2000; Murphy, McAuley et al. 2003). Many interventions have shown great initial success but failed to sustain these improvements over time, so that eventually many patients gained weight and stopped exercising (McDermott, Rowley et al. 2000). Interventions will be more sustainable if attention is paid to the cultural and historical context of the

community. Intervention teams should involve the community leaders in the programme from the start and in some cases, during the sessions of physical activity as well the dietary modifications (McDermott, Rowley et al. 2000; Murphy, McAuley et al. 2003).

Rowley et al (2000), for example studied the improvement and maintenance of physical activity, diet, body weight, blood fat and fasting glucose resulting from an intervention programme amongst a remote Australian Aboriginal community. The interventions targeted two different populations: overweight diabetic patients and the wider community. 49 overweight and obese diabetic participants took part in this study. 32 of them joined the intervention programme and 17 joined the non-intervention group. Mean BMI changed significantly in the 24 months intervention from the baseline (McDermott, Rowley et al. 2000) . Fasting plasma glucose concentration and OGTT changed significantly in the first six months but it returned to the baseline after twelve months. Fasting insulin changes was varied in its significance in both groups during the 24 month period. However there were significant differences between the intervention and non-intervention group.

The community wide intervention showed an increase in the sale of vegetables and fruit and a decrease in fatty and sugary products. The community held several sport activities as sporting festivals. Health education classes were conducted during the two years. Despite these initial successes however, it was shown that young persons gained weight during the four years of follow-up.

Narayan et al (1998), carried out an intervention with Pima Indians in Arizona. They designed two types of intervention – the first they called ‘Pima Action’ which was structured physical activity and diet. The other was called ‘Pima Pride’ which was unstructured physical activity and diet with a focus on Pima history and culture. Both groups reported an increase in physical activity during the 12 months. The Pride group reported a significant decrease in the recorded intake of energy, carbohydrates and fat. However the action group reported a non-significant decrease. Measurements such as BMI, weight, diastolic and systolic blood pressure and two hours plasma glucose increased significantly amongst the action group during the intervention. The researchers reported that it was straightforward to recruit the participants and run the intervention; but it was difficult to maintain the lifestyle changes. The intervention which involved the cultural and historical background with less structured activity yielded a more significant result compared with the structured intervention that did not give attention to cultural issues.

A special intervention to prevent Type 2 diabetes also took place amongst the Maori in New Zealand (Murphy, McAuley et al. 2003). The programme included both dietary and exercise components. The team worked with individuals concerning food nutrients. A dietician gave information about healthy food and encouraged people to eat more healthily. They also encouraged participants to exercise for 20 minutes intensively 5 times a week. The participants stressed the usefulness of regular monitoring and contact. They also reported the positive influence of weekly discussions about nutrition and the encouragement to attend the exercise sessions. Researchers reported that it was difficult to engage the family in healthy food habits

and regular exercise. They also emphasised that the availability and cost of healthy food was an issue for indigenous people with low socioeconomic status.

Hood et al (1997), conducted a community approach intervention amongst Mohawk and Kahnawake communities of native Americans in order to build a community coalition to maintain changes of lifestyle. Researchers emphasised that the main barriers the Mohawk and Kahnawake faced was a preference for large amounts of high fat food, as well as a lack of social support for lifestyle changes. Researchers illustrated that native people tended to do nothing until a problem appeared, and that they did not have the self-confidence to make changes. Researchers emphasised the fact that an intervention should be designed for each particular group; should involve key people in championing it; and should take people's historical and cultural background into account.

The evidence suggests that high commitment and high attendance at an intervention from the outset will yield better outcomes. An intervention amongst Pacific Island people in New Zealand in two communities for example, (Simmons and Voyle 2003) increased the knowledge and awareness about diabetes. Through using community members by training them to be facilitators to broker the gap between Western medicine and indigenous culture, benefits can be brought to both sides in terms of mutual understanding (Struthers, Hodge et al. 2003).

Brekke et al (2005) conducted a short intervention (16 weeks) amongst first degree relatives of people with diabetes. Their intervention divided the participants into three groups: a diet and exercise group (DE- group), a diet group (D-group) and the

third group were asked to continue their regular lifestyle (C-group). The results revealed that both groups DE and D decreased their intake of saturated fat and increased fibre intake. The DE group also reduced their weight and waist circumference.

McCulloch et al (2003), found that remote and rural indigenous people in North Queensland, Australia, adopted changes in their lifestyle to manage their diabetes. Based on self-reports the diabetic patients had similar levels of fruit consumption and exercise to non-diabetic people. However, they were less likely to smoke and drink alcohol.

In summary, the literature has shown that community based interventions amongst indigenous peoples which are focused on diet and exercise is hard to sustain. There are better chances for changes in lifestyle to be maintained if the social and cultural context is taken into consideration and if there are local champions involved in the intervention, either as individuals or as institutions.

Clinical care interventions

Interventions which focus solely on patients' behaviour cannot make the essential changes and bring about the desired outcomes if health services teams do not apply basic diabetes guidelines. According to Mak et al (2004), primary health care providers serving Canadian indigenous patients did not apply the basic standards and guidelines of diabetic clinical care, although the clinical practice guidelines of diabetes were available and the patients frequently visited the clinic.

In many cases of indigenous people, health care teams have argued that significant barriers of diabetes management were the poor compliance of patients to changes they required them to make to their lifestyles. In contrast, the patients reported that the emotional process they went through as they became diabetic, along with the limitations the disease brought, were the main barriers they faced in being able to manage it (Sunday and Eyles 2001).

The quality of clinical care in the management of diabetes is important. Clinical guidelines consist of forms or flow charts which help professionals to deal with circumstances that appear in the primary clinic. They also help the health care organisations to assess and monitor ways of dealing with health problems in the clinic.

Clinical guidelines are essential in diabetes care and treatment (Grossa 2003) They are constructed from many experts' views about tackling diabetes and the best way to treat and prevent it. The American Diabetes Association (2002) provides recommendations for nutrition principles and treatment for different levels of diabetes. The General Health Service (GHS) in Israel adopted and applied the American Diabetes Association guidelines for diabetes treatment and care for all of the physicians and primary health care teams (Grossa 2003). However these were not adapted for the Jewish Israeli population or the Bedouin.

There are inequalities in the quality of care given to patients from different ethnic groups. This may sometimes be due to communication and cultural problems but also due to inadequate standards of practice. According to a study carried out

amongst Ethiopian patients in Herziliya, a town in central Israel, the quality of treatment and follow up was significantly lower than for non-Ethiopians. The follow up measurements required the monitoring of diabetic patients for things such as blood pressure, HBA1c, lipid profile and creatinine, but these were significantly less complete than for non-Ethiopians (Yafa 2004) .

Clinical guidelines of diabetes are in use amongst health care clinics in the Bedouin community without adaptation for this population group. In Israel the General Health Service (GHS) is the main health provider, to which approximately 60% of the population is registered. Amongst the Bedouin community more than 90% are registered with the GHS. Physicians and nurses in primary care clinics receive clinical guidelines for the major chronic problems in the community such as hypertension, asthma and diabetes. They also are supposed to attend day workshops and conferences about these issues in order to maximize their use of the guidelines.

The PACIC was an instrument used by Glasgow et al (2005) in the assessment of chronic illness care and is one example of an approach that measures the quality of clinical care. The instrument would be difficult to adapt to this field setting owing to the difficulties in communication between Hebrew speaking Israeli health staff and Arabic speaking Bedouin patients. However this approach is a useful means to assess care using a standardized instrument in instances where there are less severe communication issues.

Mak et al (2004) conducted a comparative study on the quality of the clinical management of diabetes in primary care services amongst indigenous people from

remote areas in Canada and Australia. A random selection of 102 medical records of patients from Saskatchewan in remote Canada and 165 records from Kimberley, Australia were reviewed. A management checklist of diabetes was found in 8.8% of the Saskatchewan patients' medical records and in 38.3% of the Kimberley records. In Kimberley, clinical measurements such as weight, blood pressure, lipids and HbA1c were checked more often and the patients were more likely to have been screened for retinopathy. They found variations in quality management between health services in both locations. For instance the proportion of patients who had their retinopathy screened in Kimberley varied from 31% in one clinic to 89% in another. Primary health services in both locations did not meet accepted standards for the clinical care of diabetes, despite the fact that guidelines for clinical practice were available. Mak et al (2004), emphasised the need for collective efforts from health services organisations and patients to reduce the barriers to health access and tackle the epidemic of diabetes amongst indigenous people.

Conclusions

This review has critically reviewed literature concerning the increase of diabetes as a global health problem and in particular in Arab societies and amongst indigenous people . It has reviewed literature concerning explanations of health inequalities and the rights to health approach and the relevance of lay beliefs as well as on community and clinical interventions to manage diabetes. This thesis is a research study of the health and health care provision to Negev Bedouin in Israel as an example of a marginalized indigenous minority in the Arab world. The conceptual

frameworks concerning explanations of health inequalities and of a rights based approach to health will be used in this research. The research questions for this study are

To what extent can a rights based approach in terms of quality availability, accessibility and acceptability extend understandings of health and health care provision to marginalised Bedouin in the Negev, Israel who have diabetes?

To what extent can the materialist and socio-behavioural explanations of health inequalities extend understandings of the experiences and management of diabetes care and of marginalised Bedouin in the Negev?

How generalisable to Bedouin in the Arab world and other indigenous peoples is the situation of Negev Bedouin with diabetes in terms of health care and experiences of living with the condition?

The next chapter will introduce the setting of this research study.

Chapter 2

The Setting

This chapter explores the context in which this study was conducted. It begins with a review about Bedouin in the Middle East and North Africa before going on to profile Israel, taking a look at its demography in general and its southern district, the Negev, specifically. It will then focus on the history of the Bedouin in the Negev and their current situation as a minority in Israel.

Bedouin in the Middle East

The term ‘Bedouin’ came from the Arabic word (*Badoo*) which means ‘people who live in the desert’ (*Badeyah*). The Bedouin are Arab, and are thus defined as Semitic people. They speak Arabic as a mother tongue and live in more than twenty countries in the Middle East and North Africa. In social terms, researchers refer to three groups of Arabs: city dwellers (*madaneen*), village dwellers (*fellaheen*) and nomads (*badoo*) (Marx 1974; Hourani 1991; Barakat 1993).

Studies carried out regarding the Bedouin refer to this group in terms of a distinct lifestyle as opposed to a separate ethnic group. Historically all the Arabs, both in cities and villages have at some point in their history been Bedouin. The cities were settled by nomadic Arabs who had been populating the cities since the time of the Prophet Noah.

The Bedouin in the Middle East are going through a transition from a semi- nomadic lifestyle to sedentarization, leaving pastoralism and farming, and living a settled lifestyle (Bamyeh 2006 ; William et al. 2006).

The Bedouin in the past, and to a certain extent still today, consider collective interests more important than individual desires. It comes into practice with regards whom one should marry, the location of one's house and type of job. Family members, especially men, stand together in disagreements with outsiders. When a family group has an argument with another group, all the family members should support each other as "blood never becomes water" (Falah 1985; Al-Krenawi and Graham 1996; Al-Mahroos 2000). Individuals live in an interdependent relationship within the family, and consider themselves as an extension of the family group.

These values are fundamentally held (Falah 1985; Bamyeh 2006). The Bedouin have a segmentary tribal structure so that an individual belongs to a family, a sub-tribe, tribe, and tribal confederation.

The Bedouin in the Middle East faced new changes after the creation of Arab national states with the end of the French and British mandates (Spicer, 1999). The new states where they lived had different policies towards the Bedouin; for example, Saudi Arabia forced them to settle down in cities and villages, whilst the Jordanian authorities encouraged them to settle and in Lebanon and Syria the policies were not clear (Chatty 2010, Chatty 2010B).

In Lebanon historically Bedouin were nomads who moved across state borders such as the borders between Lebanon and Syria, and the first attempt to settle Bedouin

groups permanently was during the French Mandate in the 1920s and the 1930s (Leybourne , 1993, Chatty, 2010C). Bedouin are roughly estimated to represent 2-3% (100,000-150000) of the population in Lebanon (El Kak, 2011 & Chatty, 2010). They live in peripheral agricultural and rural areas. Bedouin people themselves started to settle in illegal settlements in the Bekaa Valley after they found they were losing space to move as a result of privatisation of land which decreased the pasture available for their livestock. Bedouin were also experiencing attacks from the police and government officers and their tents were burnt or pulled down.

Successive Lebanese governments have not included the areas where Bedouin lived in their development plans, therefore there were a lack of policies to deal with the Bedouin special lifestyle and livelihood strategies. The areas they lived in were left without infrastructure, such as sanitation, water electricity or roads.

In recent years, Bedouin in Lebanon have gone through political, social and economic changes. The peak of the socio-political changes was in 1994 when a new Normalisation law came into effect. The Lebanese government, as result of the political electoral tensions, granted some of the Bedouin and other groups the right to Lebanese nationality. However this was halted after the Lebanese Maronite League submitted an appeal against the law (Chatty, 2010) for political reasons. They did this because regularising the nationality of Bedouin in Lebanon would increase the number of Sunni Muslims and change the sectarian balance and power status between the different groups in Lebanon.

In Syria, there is a little information about the relationships between the Syrian authorities and the Bedouin, although the overview is that Ba'th regime wish to introduce changes in the Bedouin tribal social structure. The contact is usually established between the governor of the area and the tribal leaders. There were persistent attempts from the Syrian authority to change the close relationship and functions of the tribes and apply the law to exert more control of Bedouin, however, the Bedouin continue in their traditional lifestyle and tribal structures which gives them protection and solidarity (Chatty, 2010B).

In the 1950s, the Ba'th regime legalised the status of Bedouin, and also recognised Bedouin customary law for tribal matters . However, the regime constantly attempted to modify the nomads' lifestyle. The Ba'th regime has avoided confrontation with the Bedouin although the current uprising in Syria has resulted in tribes being actively involved in fighting the Assad regime (Chatty, 2010B).

In Jordan, Bedouin were encouraged to settle in villages. The majority of them have governmental services such as electricity and running water, schools and clinics. Many Bedouin in Jordan serve in the army and other public services. The Bedouin formed the Arab Legion that has protected the Hashemite monarchy and they have representation in Parliament. Owing to serving in the army, they also have access to clinics and schools provided by the army. They are marginal in terms of where they live in the country but they are not so marginal in terms of political power (Oudat and Alshboul 2010, Spicer, 1999).

In Israel, the Bedouin are citizens like the Bedouin in Jordan but unlike the Bedouin in Syria. Similarly, they have been encouraged to settle in villages but these involve displacement from their grazing and agricultural land and an urban lifestyle. Those Bedouin in Israel who do not wish to live in a government planned village live in unrecognised villages without infrastructure which is similar to the disadvantaged living conditions of Lebanese Bedouin.

Bedouin and Access to Health Care

The basic health services for Bedouin is problematic in the Middle East for several reasons, including the distance of their living areas from health services , living in informal settlements which lack infrastructure, and their mobile lifestyle which limits their access to health services

All Lebanon citizens have access to health care provided by the government which is subsidised by different sectarian groups, but governmental health care is weak and fragmented and service provision is mostly private or through NGOs. Therefore, the majority of the Bedouin in Lebanon lack nationality status and therefore have no rights to government health care. Furthermore, it has to be said, that government health care in rural areas in Lebanon is poor. Owing to their lack of citizenship and poor government health services Bedouin lacked to access to health services. In addition, Bedouin in Lebanon experience discrimination towards them in Lebanon society. El Kak (2011) interviewed policymakers sectors in Lebanon, and found that they had negative stereotypes about the Bedouin. Sentences like “living out of the society”, “marginalise themselves”, “illiterate”, “having big families” and “engage

in illegitimate behaviour” (El Kak 2011). The policy makers had also inadequate information about the Bedouin socially, geographically and concerning their health problems.

Marginalisation and neglect of the health needs of Bedouin and other groups in rural areas was consistent in the policies of Lebanese governments during the last several decades. Regardless of the complications of the citizenship status of Bedouin, the policy makers were not able to recognise the special health needs of the Bedouin and or how to improve health care delivery. For example, the immunization programme is one of the major health services that are offered in primary care to Bedouin; however this service did not reach many Bedouin children. School vaccinations were treated similarly (El Kak 2011).

Bedouin experienced discrimination based on their ethnicity and social group in the health centres. This was expressed in different forms such as miscommunication of information, extra waiting time, incomplete medical records and arrogant health staff’s attitudes. The staffs were not Bedouin and were generally from urban areas.

Bedouin women experienced institutionalised ethnic discrimination in the reproductive health and other general health issues in Lebanon (Mansour, 2010). In additional, Mansour (2010) found that Bedouin women shared similar constraints with other marginalised groups such as overcrowded facilities, long waiting times, high cost of medical services because of lack of citizenship and lack or unclear information about accessing medical financial assistance.

In Jordan, the situation of Bedouin is different owing to both their citizenship, their status within the country, and the strong governmental and military health services provision. Bedouin can use two different health service providers – the Ministry of Health provides primary health care including preventive and curative care as do the Royal Medical Services.

According to Lewando-Hundt et al (2012), there are issues about the quality, availability, accessibility and acceptability of health care in the north eastern desert area of Jordan. There are many small clinics but sometimes the distance from some Bedouin houses to clinics can be far (75km). In order to overcome this problem the Royal Medical Services and the Ministry of Health had some mobile units for vaccinations for Bedouin in remote areas.

Most of the health professionals working in amongst Bedouin are city dwellers and have limited knowledge and understanding about Bedouin culture in East North Badia. They also have negative stereotypes about them. There is a lack of female doctors and nurses which makes the services less acceptable, both policy makers and health professionals are aware of these shortcomings and are trying to address them (Lewando Hundt et al. 2012). In Saudi Arabia they have tended to address the Bedouin health issues in the context of rural areas where there have been many problems in the delivery of health care (Qureshi, 1996). Bedouin women have very high fertility rate in Bekaa, Lebanon. However there are indicators that the rate is gradually declining as a result of modernisation as the reliance on traditional lifestyles is reduced with the move to wage labour (Joseph, 2004).

Improving the access to health care services amongst Bedouin in developing countries is problematic because of their mobility and because they inhabit remote areas and live in isolated geographical areas where health services usually less provided (Chatty 2010, Spicer 2005).

Many factors have been identified by researchers to influence the utilization of health services in rural areas including geographical, economic, and social and cultural. The geographical factors include the distance and availability of transportation and its cost. The cost likely restrict the use the health services, medication and tests. The relationship between users and health services providers and the communication could play important role when it comes to use the services (Spicer 2005).

There are similarities in living conditions between Bedouin in the Bakaa Valley in Lebanon and in the North Eastern Desert of Jordan and in the Negev in Israel. However the Bedouin in Israel were granted nationality after the establishment of the state of Israel establishment and are provided with health care and have universal health insurance unlike the Bedouin in Lebanon (Joseph 2004, Mansour, 2011).

Negative attitudes of health care professionals (often with an urban background) towards Bedouin as a marginalised group who live differently and a lack of sympathy and knowledge about their lifestyle is reported by research carried out in Lebanon (El Kak 2011), Jordan ((Lewando Hundt et al 2012) and will be evident in the results of this thesis. One of the contributions of this study is to provide new empirical data from the Negev, Israel concerning the quality of health care being

provided to Bedouin and its availability, accessibility and acceptability as part of the universal right to health care.

The Bedouin in Israel

This research focuses on the Bedouin who live in the Negev. There are a few Bedouin villages in central and northern Israel numbering approximately 50,000 but they are not part of the research area. The Negev is a semi-arid zone in the south of Israel covering an area of 4,600 square miles, and comprising over 66% of Israel (over 6,700 square miles) (Israel Land Fund, retrieved on 05/07/2011).

Figure 2.1: The Negev desert map.



Source: <http://thenewjew.wordpress.com/2009/07/07/israeli-environment-new-mall-seeks-to-green-the-negev/>

Originally Bedouin were semi nomadic pastoralists and some of them arrived in the Negev in about 600AD. Prior to this time there were Nabatean cities in the Negev – Avdat, Kurnub, Halasa and Shivta linked to Petra along spice trade routes to the coast where the main port was Gaza (Korjenkov and Mazor, 1999). The Byzantines then took over these cities in about 200AD before being defeated by the Arabs from the Arabian Peninsula. Some Bedouin came more recently during the 19th and 20th centuries during the Ottoman empire (Lewando- Hundt 1988).

In 1948 during what the Israelis call the ‘War of Independence’ and the Palestinians call ‘The Catastrophe’ (Al Nakba) (Chatty and Lewando-Hundt 2005), about 80% of the Negev Bedouin population were expelled from their lands or fled to Jordan and Sinai in Egypt. Only 13,000 out of 65,000- 95,000 remained in the country (Marx 1974; Al-Krenawi 2004). They all lived in a reserve under military occupation with restricted movement in the North Eastern Negev with some tribes remaining on their land and others being displaced and joining them. The tribes with grazing land in the Western Negev where there was more rainfall were displaced and the land used for the establishment of communal agricultural settlements (moshavim and kibbutzim), development towns for new Jewish immigrants, and for military manouvres and bases. The reserve under a military authority continued until 1967 during which time freedom of movement was allowed (Marx 1967; Marx 1974).

As a direct consequence of the establishment of the State of Israel, the Bedouin lost most of their land, and their livelihoods as semi- nomadic pastoralists. They became an indigenous minority within the State of Israel. Owing to a lack of pasture and restricted movement, flocks were reduced. This meant that the process of

sedentarization began in the 1950s. The Israeli government from the 1970s pursued a policy of planned sedentarization with recognised designated towns for Bedouin where they could build houses with access to mortgages at low rates of interest.

There was no private ownership of land for grazing or agriculture. Land was available to rent from the State for these purposes but there was no water available. Irrigated agriculture only occurred in Jewish communal agricultural settlements.

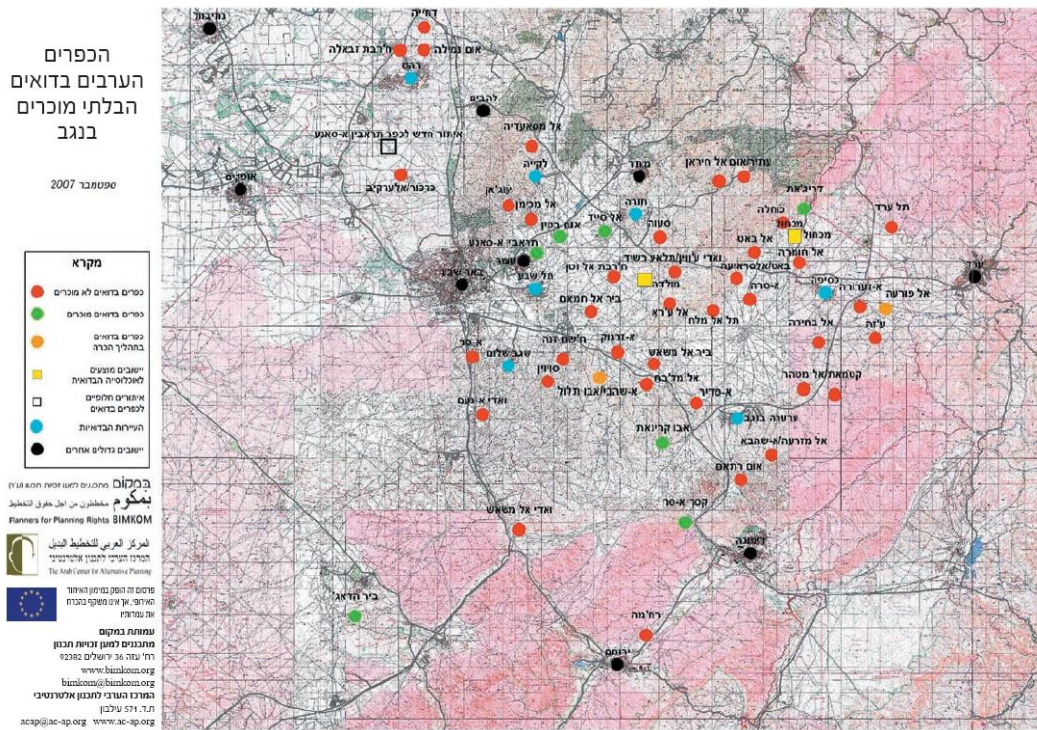
Many of the Bedouin, particularly those still with land, refused to move to these designated planned towns despite these having schools, clinics, electricity and water, and instead continued living on their land in encampments and huts in villages, not recognised by the State authorities and therefore lacking in running water and infrastructure.

The process of settling the Bedouin in urban villages started in 1969 when the first Bedouin village was established, Tel Sheva, which was then followed by another 6 villages (Rahat in 1971, Segev Shalom in 1979, Aroer and Kuseife in 1982 Laqiya in 1985 and Hura in 1989). Rahat is very large with a population of approximately 50,000 and has the status of a town. Since 1999 another nine unrecognized villages (Um-Batin, Gassar al-Ser, Al-Grain, Um-Matnan , Bir Hadaj, Makhul, Wadi Gowein , Tarabin, Drijat) had received recognition from the state and they are in different stage of the planning process. Almost all of these villages still have no electricity, road and water systems and no building infrastructure yet because of land ownership problems. At the end of 2010, the estimation was that 55-60% of Bedouin were living in these recognised villages and town. However, as set out above, many of Bedouin defined within this 60% were living without the infrastructure of an

established settlement. The rest of Bedouin, lived in dozens of unrecognized villages that do not appear on official state maps (Negev Coexistence Forum, 2010).

Bedouin living in these unrecognised villages and in the undeveloped recognised villages live in huts similar to the shanty towns that exist in peri-urban areas in South America or Africa. These villages have no infrastructure for water, electricity, sewage, roads, health services, education, garbage disposal, or other public services.

Map 2.2 Bedouin Negev villages



(Source: BIMKOM – Planners for Planning Rights and The Arab Center for Alternative Planning)

- Legend
- Unrecognized Bedouin Villages
 - Recognized Bedouin Villages
 - Bedouin Villages in Recognition Process
 - Towns offered to the Bedouin Arabs Population
 - Alternative places for Bedouin Villages
 - Bedouin Towns
 - Other Large settlements

According to the Israeli Central Bureau of Statistics (CBS, 2012), the population in Israel was 7,836,600 in 2011, of whom 75.4% were Jewish. Of the non-Jewish population, 20.4% were defined as Arab and 4.2% were categorised as other. The Bedouin are included with other Arabs. The Bedouin are concentrated in the southern district and comprise the total Arab population. There were 1,121,600 inhabitants in the southern district which consists of two sub-districts: Ashqelon and Beer-Sheba (see map 2.3). The Ashqelon sub-district is primarily Jewish. In the Beer-Sheba sub-district there were approximately 204,700 Bedouin from a total population of 634,500 and the Bedouin comprised 31% of the Negev sub-district population (CBS 2012).

Figure 2.3 Negev district in Israeli districts map



Source: <http://www.mapsofworld.com/israel/israel-political-map.html>

Life style transition, poverty and Bedouin health

Bedouin like many Arab and indigenous populations around the world have experienced rapid changes in their lifestyle. They have become increasingly urbanised and ‘westernised’. The process has affected Bedouin lifestyle, including daily activities, social life and economic status. Consequently, Bedouin livelihood strategies have changed dramatically in the last half century (Ben-Assa 1964; Abu-Rabiah and Weitzman 2002). In the past, their economy relied on herding and agriculture; a semi nomadic means of subsistence. The family usually kept a herd of sheep and goats and people used the wool and milk to create their own products—carpets, tents, fodder, flour and cheese, whilst selling the surplus. They used to grow and harvest barley and wheat from winter rain and stored most of it for fodder for their flock and flour for their families. Traditionally, men worked in the public sphere selling sheep, finding grazing, negotiating tribal affairs and women worked in the domestic sphere and also herded sheep and harvested crops with their menfolk and children (Lewando-Hundt 1988). This meant that women like men did a lot of physical activity, outside the home and in the company of other family members. In addition women were responsible for fetching water and fire wood and food preparation. As children grew older they also took part in these activities.

Today, most men work as unskilled or skilled manual labourers with low wages and in poor conditions. For example, many work in agricultural seasonal labour, on building sites or in factories. Today the Bedouin have the highest rate of unemployment in Israel. The Bedouin recognised villages sit in the lowest socio-economic bracket in Israel (see Table 2.1). It is believed that the rate is much higher

in the unrecognised villages. There are many disparities within the Israeli population amongst both the Jews and the Arabs. The Bedouin however are at the bottom of all these measurements. Some of the health measurements have improved over time such as a decrease in infectious diseases such as TB. However, they are now exposed to new types of chronic disease such as diabetes, hypertension and cardiovascular diseases that reflect the transition to an urban way of life.

Table 5.1: Negev Local Councils and Municipalities by Socio-Economic Ranking (0<210), (CBS, 2001). Higher rank indicated by higher number

Locality	Rank
Kseifa (Bedouin)	2
Tel Sheba (Bedouin)	1
Laqiya (Bedouin)	9
Dimona (Jewish)	97
Beer Sheba (Jewish)	124
Omer (Jewish)	209

Source: Israeli Central Bureau of Statistics 2001.

Some Bedouin, mostly young professionals, live in the main towns particularly Beer Sheba. Residence is to some extent ethnically segregated as is the educational and health provision, this situation however was not specifically legislated until a recent law passed in 2011 stating that an Arab cannot purchase a house in a Jewish community which has less than 500 people. Prior to this there were informal

barriers such as army service for being eligible to live in a new suburb outside main towns.

Today, the educational situation of the Bedouin is the worst in Israel. There is a high dropout rate of boys and girls from schools that are of a poor standard. The dropout rate is higher amongst those living in shanty towns than in planned towns. The number of Bedouin attending higher education has increased dramatically during the last decade, however the proportion is still very small compared to Jews and other Arabs in Israel. The significant change in the take up of higher education has occurred amongst girls (Abu-Saad 1997; Abu-Saad 2004; Abu-Saad 2004; Abu Rabia Queder 2006). During the last 20 years, the Bedouin education system has come under scrutiny and much research has been carried out both by Bedouin and Jewish researchers.

In comparison to the past, there is an improvement in the education system in terms of buildings, number of high degree holders, especially amongst women (Abu-Rabia-Queder and Arar 2011), however the numbers are still far away from keeping pace with progress made by the general Arab and Jewish education levels (Abu-Saad 1995; Abu-Saad 1997; Abu-Saad 2004). Abu-Saad, has written many articles about the Bedouin education system, arguing that although the military government (*Mimshal Tzvai*) officially ended in 1966, its continuous legacy still shapes the Palestinian Arab life of Israel in general and Bedouin in specific. The education provision in the whole sector but especially in the unrecognised villages is poor (Abu-Saad 1995).

Bedouin society is patrilineal. The head of the family is the oldest male of the extended family. When the head of a family dies another male replaces him, usually the oldest brother or son. Daily life decisions such as going to a clinic, shopping or visiting members of the family, are negotiated by women with men making the formal decisions but with women having informal power and influence (Lewando Hundt 1984). Clearly there is much variation but it is a patriarchal society with women's influence increasing as they themselves get older and have grown children. Many families still require men to accompany women when they leave the house, go to the clinic, or go to town. The women have more freedom of movement if they are in a group of women.

Tribes are divided into sub-tribes, which are built of extended families who live next to each other. In an encampment this is a cluster of tents, and in villages adjacent huts or houses are constructed within sub-tribal neighbourhoods. After marriage the woman joins her husband's family and the new couple live next to his parents' home so Bedouin society is both patrilineal and patrilocal (Al-Krenawi and Graham 2001; Al-Krenawi and Graham 2001).

There is usually a central house for the whole group to gather, this is normally the father's house. This house is called (*Beet El-elah*) - family house. It has a guest section (*shiq*) which is where men gather to discuss family issues such as marriage, and solving problems amongst themselves or with others. It is also the place where family's events are held such as celebrating new babies being born, Muslim holidays and circumcisions. It is also the place where guests are received

As in many Arab societies parallel and cross cousin marriage is the preferred form of marriage and in some cases may be accountable for some congenital anomalies. For example, exceptionally high rates of deafness occur within a certain sub-tribe (Kisch, 2008). Polygamy is widely practiced (Al-Krenawi et al, 1997, Al-Krenawi and Graham, 2006).

Today the majority of Bedouin work as skilled labourers in the cities or work in the public services as teachers in Bedouin schools, secretaries, doctors and nurses, or as ship-owners. It is acceptable for women to work outside the home, but this is limited to a few types of employment mainly in teaching, in clerical roles or in nursing.

Although more boys attend high school, more girls take up higher education than boys as it is seen as a socially acceptable way to leave home (Abu-Saad 1997, Abu Rabia Queder 2006). Education has empowered young women and allowed them to work in better jobs compared to men. This has allowed a few women to take leadership and work for their communities. Today there are organisations which are run by Negev Bedouin women and they work mainly to empower the community and advocate for it. For example the coexistence forum is a group of educated activists from Bedouin and Jewish communities working together to improve the Bedouin situation especially concerning the right to land and campaigning against the demolition of houses. Sedra is an organisation which was established, in Laqiya - which is one of recognised Bedouin villages-, by Bedouin women to improve Bedouin women's economic situation by providing them with opportunities to work from home at traditional weaving (Marteu 2005).

More than 50% of the Bedouin are between the age of twelve years and six months (CBS 2012). However they differ as a population from countries at an early stage of health transition because their fertility rate is considered to be one of the highest in the world (8.97 %) and the annual growth rate is 5.3% (CBS 2012). This situation can be attributed to universal access to ante-natal care and hospital delivery, women bearing children throughout their reproductive life cycle with early marriage and little use of contraception and a plentiful food supply (Kisch 2009).

Health services

In 1995 the National Health Insurance (NHI) Law was introduced in Israel which ensured universal insurance coverage for all citizens and defined the responsibility of the state to supply a detailed basic basket of services (Gross et al 2001). The law stated the duties of the Ministry of Health such as priority setting, planning and supervision of health care providers. It also provides individual preventive care such as pre- and post-pregnancy health care to mothers and children, psychiatric and geriatric care, and rehabilitative care. The health care providers through Health Maintenance Organisations (HMOs known as Sick Funds in Israel, were responsible for providing primary secondary and hospitalisation health care (Gross et al 2001). There are four health care providers, Clalit health services is the largest one with a coverage of 53% of total population in 2007, followed by Maccabi (24%), Meuhedet (13%) and Leumit (10%) (Rosen and Samuel 2009). 75% of Arabs in Israel are registered with Clalit (Levin-Zamir, 2009) which was historically linked to the major trade union of the Labour party (Histadrut) and is the main provider to the

Bedouin and to the rest of the population. It also owns hospitals including the one in Beersheva, the Soroka Medical Centre serving the region.

The Negev as a rural region has a lower availability of health care services and shortage of health professionals in Israel (Avniri 2011). In December 2009, there were 30 health care clinics serving in the Bedouin community, 11 from them in the new recognised villages and 8 Mother and Child clinics run by the Ministry of Health offering pre-natal care and immunization of children(Avniri 2011, Bilenko, Hammel et al. 2007). Families living in small encampments and unrecognised villages use the clinics in the recognised villages which involves some travelling. The average doctor patient ratio in the unrecognised villages is one doctor to 3116 residents. The doctor-patient ratio is one doctor for every 892 residents in similar sized Jewish settlements such as Negev Kibbutzim like Sde Boker, or Revivim. The nurse-patient ratio for Bedouin is one nurse for 3751 patients and for Jews living in rural settlements in the Negev is one for 657 patients. In addition, the average weekly hours for doctor per 1,000 residents in the Bedouin villages was 13 hours per week for every 1,000 residents, compared with 21 hours in the Jewish rural settlements (Avniri 2011). Considering that 50% of the Bedouin population are 12 and under and that family size is bigger, this disparity involves a lack of paediatric provision.

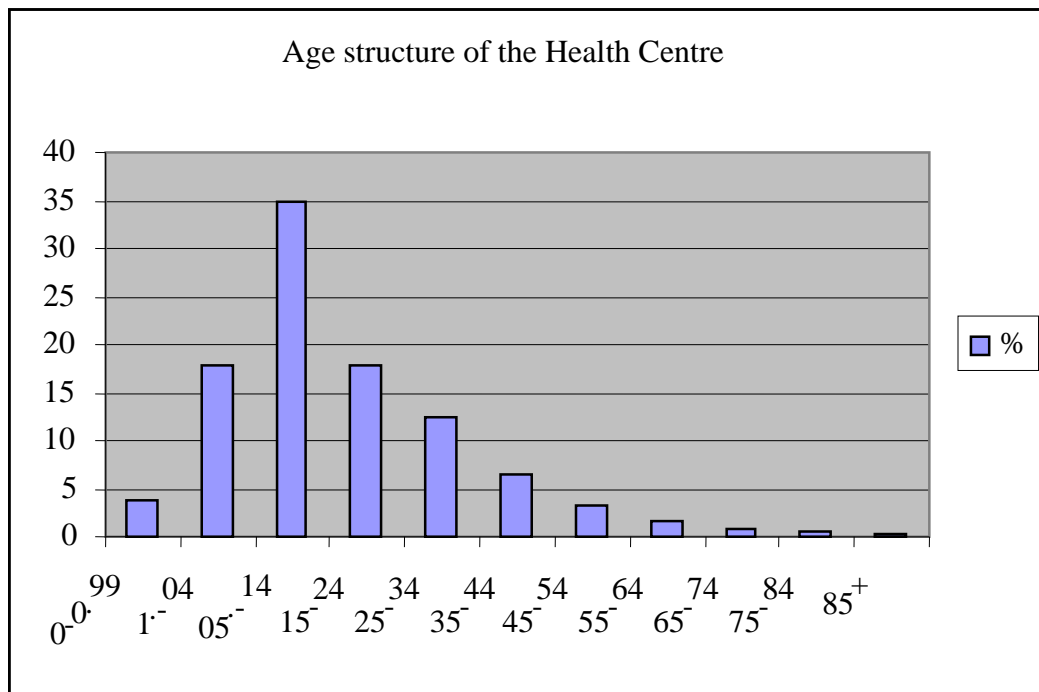
There have been dramatic changes in the health status of Bedouin. Prior to 1960, diabetes and obesity were largely unknown in the Bedouin population (Ben-Assa, 1964). They have now become major public health problems (Ben-Assa 1964; Weitzman, Lehman et al. 1974; Abu-Rabiah and Weitzman 2002). According to

Abu-Rabiah and Weitzman (2002) the prevalence of diabetes amongst Bedouin was twice the prevalence of that previously reported among Jews in Beer-Sheva in a nationwide survey (Stern, Raz et al. 1999).

According to studies carried out amongst the Negev Bedouin society in southern Israel, diabetes and obesity are becoming a major health problem (Abu-Saad, Weitzman et al. 2001; Abu-Rabiah and Weitzman 2002; Cohen, Gefen et al. 2005). A study by Cohen et al (2005), indicated that 15% of the subjects living in urban areas were obese and 35% were overweight compared to 23% being overweight and zero obesity in rural areas. Abu-Rabiah & Weitzman (2002) found that the mean body mass index (BMI) was high among the Bedouin community, particularly amongst women.

Another significant health indicator is birth rate. It is very high amongst the Bedouin and families tend to be large with an average of ten children. In addition the total fertility rate is much higher amongst Bedouin compared to Arabs and Jews in Israel, which stand at 7.6, 3.7 and 2.7 respectively. The majority of the Bedouin population is children. The median age in the population is 12.5 (See figure 2).

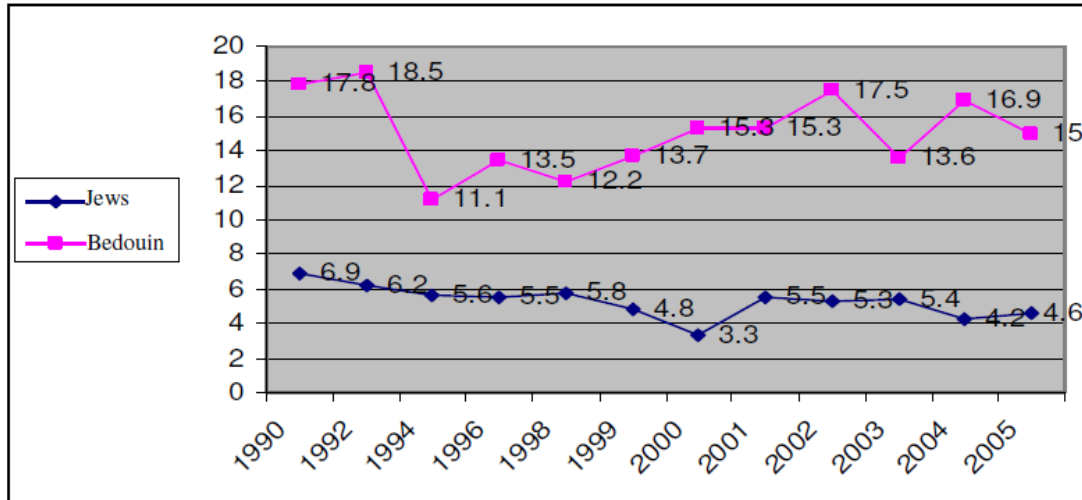
Figure 2.2: Age structure of the Health Centre 2006.



Source: Health Centre Internal Report (2006)

Infant mortality is considered to be a sensitive indicator of socio-economic differences relating to the health of a population. The rate was 14.1 amongst the Bedouin and 2.9 amongst the Jewish population in the Negev see figure 2.3 (Central Bureau of Statistic 2006). This reflects the differences in lifestyle and socio-economic circumstances between Bedouin and Jewish populations in the Negev in Israel and is similar to the gaps in infant mortality rates between the white and indigenous South Africans over many years.

Figure 2.3: Infant Mortality Rate in the South According to Population Groups during Selected Years between 1990 – 2005 (Per 1,000 Live Births). Negev Coexistence Forum, (2010)



In the context of this research study, it is clear that materialist, neo materialist and socio-behavioural explanations of health inequalities are relevant to an analysis of the health of the Negev Bedouin in general, and to an analysis of diabetes and obesity in particular.

Most of the health workers in the clinics serving the Bedouin towns and villages are not native Arabic speakers as there are few Bedouin nurses and doctors. Most of the non-Bedouin health professionals have a limited knowledge of Bedouin culture and lifestyle.

Bedouin Households

Today, Negev Bedouin like other Bedouin in the region and many indigenous people live in poverty. They live in bad housing condition with poor infrastructure in recognized villages, and non-existent infrastructure provisions in unrecognized

villages. There is lack of public transportation, lack of road and sewage networks, no running water nor public services in many unrecognized villages, and only insufficient levels of service in recognized villages. Bedouin families whether they live in recognised or unrecognised villages keep their traditional customs around cooking and serving food (Abu Saad 2002).

In the past, when the Negev Bedouin lived a semi nomadic lifestyle their traditional lifestyle provided them with healthy food and required massive amount of physical activities to maintain their life. The changes from semi nomadism to sedentarization are bringing transformation to their food consumption patterns.

Owing to sedentarization the diet has changed so that, for example, the use of fats and oil has risen significantly. Bread is the main dietary staple for the Bedouin and it supplies 32.7% of the total energy intake (Abu-Saad et al, 2009). The bread is usually made at home from white flour bought in a nearby town in 50kg sacks.

These days, in Bedouin villages, there are occasionally a few bakeries, however only a small percentage of Bedouin actually buy bread, and it is more common to employ women to bake, such as occasions when a woman might be spending a long time away from the house if she is ill. The majority of Bedouin still make bread at home on a daily basis. Common ingredients used in meals include vegetables and legumes, which are cooked by women and girls.

The Bedouin do their shopping in the main city of Beer-Sheba, buying goods that they need such as food stuffs, clothes and medication (if these are not available in their clinics). Men usually buy the ingredients. However, nowadays there are slight

changes, and in the recognised planned villages a weekly market takes place. This facilitates access to fresh food and allows women living in the village to buy food products. People living in unrecognised villages however still need to make long trips to the city or the planned villages to buy their groceries.

In the past, the Bedouin cultivated some of their food from agriculture and livestock. Each family planted winter crops mostly wheat, barley, lentils and chick peas on their land and vegetables in small dams which collected water during the winter rains. Occasionally they also grew olives, grapes, figs, almonds, pomegranates, dates and cacti. Each family had a flock of sheep, some goats and camels. As they moved to villages chickens were kept for poultry and eggs in some families (Lewando Hundt 1984; Lewando Hundt 1988).

In the past, the Bedouin's daily diet was low in fat, and a typical meal consisted of bread eaten with vegetables or pulse stews, such as lentils with tomato puree for example. Poultry and meat were eaten only occasionally because of their high cost. Meat was customarily saved for weekends when the whole family gathered (as many of the Bedouin men work in towns in the centre of the country) or when guests were present. Traditionally, the chicken would have been boiled and served with rice and bread. Sheep and goats were slaughtered and eaten at events such as weddings, circumcisions, celebrating guests and at Eid Al-Adha (Festival of Sacrifice) and Eid Al Fitr.

In the past the Bedouin commonly drank black tea and coffee. Whilst in the spring time they drank milk from the sheep and goats. However, recently soft drinks and

juices have entered the Bedouin diet and become an essential part of meals. It has become part of good hospitality to greet guests with soft drinks, which are sold in the local shops.

Many studies have found that food ingredients have a strong correlation with being overweight and obesity. These are risk factors for chronic diseases, especially diabetes. Diets that contain a high rate of saturated fat, cholesterol and a high intake of carbohydrates have a strong correlation with a prevalence of diabetes (Marshall, Grunwald et al. 2000 ; Smith and Wiedman 2001; Van-Dam, Willett et al. 2002; Otukonyong, Dube et al. 2005). Today, the Bedouin diet contains high amounts of fat and sugar. Coca cola especially has become very common. In addition processed, canned and preserved food is now consumed more often. Many dishes have high amounts of fat and fried food, such as upside-down (*maqluba*), which became a traditional dish amongst Bedouin who learnt it from Palestinian city dwellers. The dish consists of fried vegetables and chicken which is arranged in layers and cooked together slowly before being served upside down in a large bowl (Abu-Saad, Weitzman et al. 2001; Wright 2007 ; Abu-Saad, Shai et al. 2009).

Conclusions

This chapter has set out the social and historical context of the study. Bedouin have lived throughout the Middle East in Arab societies for many centuries. The Bedouin in the Negev migrated from the Arabian Peninsula close to 1500 years ago and so they have lived in the Negev for many centuries. Most Bedouin living within modern nation states have had to relinquish pastoralism as their main means of livelihood. In the Negev, the Bedouin have been going through a transition process since 1948. In 1962, the first Bedouin village was established, as the state decided to move the Bedouin from a lifestyle of agro-pastoralism (Ben-David and Gonen 2001). Negev Bedouin live in either planned towns and villages with facilities, or unrecognised villages or encampments which lack infrastructure, running water, electricity and services.

The Bedouin in the Negev are part of a Palestinian Arab minority within Israel, and like some Bedouin elsewhere in the Arab world and other indigenous peoples are politically, socially and economically marginalized. The next chapter will address the research methodology.

Chapter 3

Research Methodology and Methods

This chapter will discuss the methodology and methods of the research study on the management of diabetes undertaken with Bedouin patients, their families and health professionals in the Negev.

My epistemological approach was inductive and interpretive and influenced by social constructivism (Avis 2005). The focus of the research was to elicit knowledge regarding lay beliefs, understandings and the daily management of diabetes amongst Bedouin patients (Druckman 2005) through ethnographic fieldwork including non participant observation and interviews. It also aimed to recognise the health provider services practice in order to understand the policies decision making when it came to Bedouin people health. It is important to develop knowledge of the meanings attached to diabetes in daily Bedouin life, how the disease is understood by them and how it is interpreted in their daily lives.

I chose to use a case study framework. A case study approach is usually used to answer 'how' and 'why' questions, and in situations in which the researcher has little or no control over contemporary events in a particular setting (Yin 2009).

These conditions were therefore applicable to this research amongst Bedouin in the Negev.

Both quantitative and qualitative methods were used in this case study. Quantitative methods identify and outline the size and extent of a problem, whilst qualitative methods provide data on the contextual and conceptual basis of beliefs and practices (Silverman 2005). The use of these different approaches has allowed for some triangulation which helps to strengthen the reliability and validity of the data (Bell 2005 ; Bryman 2006).

The purpose of the case study was twofold. Firstly, the study aimed to extend knowledge of Bedouin patients' beliefs, understanding and self-management regarding diabetes. Secondly, it was to explore and analyse the ways health professionals practice their day to day care in clinic settings. To achieve these goals, I used a range of qualitative methods as part of ethnographic fieldwork. I conducted non participant observation (Atkinson and Hammersley 1998) observing the routine daily work in clinics; held semi-structured interviews with patients and health professionals and conducted natural group household interviews. Quantitatively, I conducted a clinical record review and analysed the data to establish the level of diabetes control through clinical measurements (Mason 1994 ; Blaxter et al. 2006).

Fieldwork setting

My fieldwork was carried out in two settings – at a health centre and at an outpatient diabetic clinic in a hospital in the main town nearby.

Approximately 70% of Bedouin patients attend Clalit Health Services (CHS) clinics, while the other 30% attend clinics at three other health maintenance organizations (HMO). The Bedouin who attend a clinic can be clearly identified by

their identification card (ID) numbers from the computerised system. Clinic records are identified by the ID numbers which are issued at birth to individuals in Israel. All adults carry their own identity card. The data in the clinical records include gender, age, type of diabetes, BMI, HbA1c and the date of diagnosis. Data analysis of clinic records is set out and discussed in chapter 5.

Pilot Study

I carried out a pilot study of this research in February and March 2007, after I had obtained ethical approval. I chose my interviewees for the pilot study from the community without involvement from the clinics. The actual fieldwork was then conducted between August and December 2007.

In the pilot study, I interviewed nine diabetic patients in their homes. These were carried out in order to fine tune the semi-structured interview topic guide and to trial ways of approaching the relevant topics. The nine patients were chosen by snowball sampling, and included four men and five women from Tel-Sheva Bedouin village and the Abu-Qrinat tribe. After conducting these interviews, I changed the order of some of the topics and the ways in which I planned to ask them. For example, I found in the pilot study that people started talking about their traditional medicine when talking about their clinic medication, thus I changed the order in which I asked a question about using traditional medicine so that I could now ask it after I finished a set of questions regarding routine review and medication in the health centre.

Negotiating access to the Clinics

Prior to beginning my field work I obtained ethics approval from the University of Warwick, the Helsinki committee in Soroka University Hospital, Beer-Sheba and the research committee of Clalit Health Services in Beer-Sheba. As the Helsinki committee regulations do not allow nurses and other health sciences students to carry out independent research, a senior consultant for diabetes helped me obtain the committee's approval, since only physicians or researchers with doctoral degree are allowed to be the signatories on any application forms.

I faced several difficulties in the process of obtaining the ethics approval from the Helsinki committee. It was difficult to make contact with the committee office in order to find out regulations and procedures for requesting permission, while an obstructive gatekeeper made obtaining the forms the most difficult step. There is no website for the committee to allow one to obtain information regarding procedures, regulations, date of submission and other related forms. When I contacted the committee office the secretary was uncooperative, and refused to provide the forms. Instead she asked me to download the forms and the guidelines from CHS website which is a professional website that only CHS employees can log on to with a registered name and password. Despite my explanations to her, she still refused, though she apparently cooperated with other researchers. Finally a former committee member provided me with the form I required after I contacted him and explained the situation. After the forms were filled, the diabetic consultant signed them as the main researcher. Three weeks on from my submission date I received approval for the research. With the Helsinki committee's approval letter I submitted the proposal

and filled the forms for the CHS Research Committee. Again, the research committee required me to obtain the signature of a physician from the health centre where I wanted to do the research. The permission was granted without query or delay.

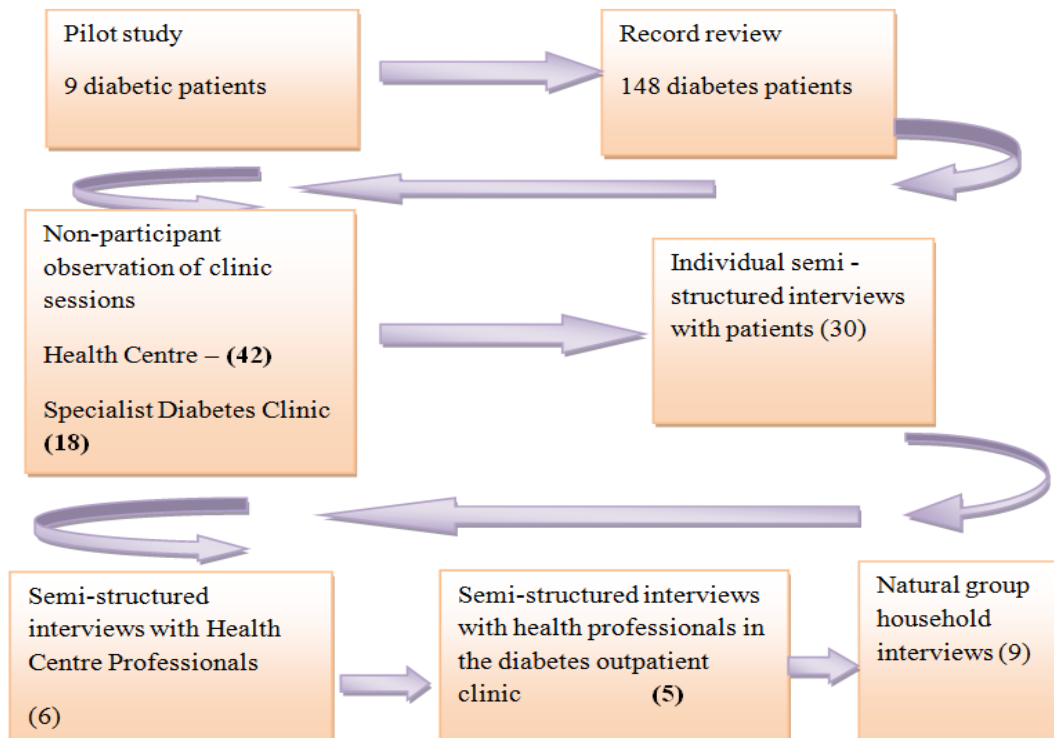
Following this I officially contacted the health centre manager of a CHS in a large Bedouin village in the North Eastern Negev health centre where I wanted to conduct my study. This site was chosen because it was in an area I had not worked as a nurse previously and where I had no relatives nor ties to any of the tribes in the immediate area. I visited the health centre, met the staff and introduced myself. I explained the research aims and process, and requested their consent and cooperation.

The health centre was located in the centre of the aforementioned village close to the local schools and the village council building. The health centre building was small with inadequately few rooms for the staff, which became especially noticeable on days when specialists came to see patients. They therefore asked me to come and observe only two days a week. Wednesday was the day usually booked for diabetic patients and other chronic conditions such hypertension and asthma. I also chose to go on either on a Tuesday or a Thursday depending on my interview schedule.

In order to access the clinic's record systems I needed a login name and password. The ethical approval from the CHS allowed me to view the diabetic patients' records, however they did not provide me with a login name as this was provided for employees only. Usually a staff member logged me in using his or her name.

In order to estimate the prevalence of diabetes and other related clinical measures, a diabetes report from the computer was obtained through the computer programme used in CHS clinics. This report contained data about diabetes clinical measures, patients' names and identification card numbers. Additionally, I received two handwritten lists from the two nurses responsible for the follow-up of diabetic patients. The lists contained patients' names and ID numbers and few clinical measures such their treatment type and HbA_{1c}. HbA_{1c} is defined as a substance that show the level of glucose sticks to the haemoglobin to build up a 'glycosylated haemoglobin' molecule in the last the months. This period is the life time of the red blood cell. When the glucose levels are high in the blood the result would show high HbA_{1c}. A normal result for non-diabetic person is when HbA_{1c} is 3.5-5.5% and for diabetic patient when less than 6.5% is good' (World Health Organization 2006).

Figure 3.1: Chart of Data.



Quantitative methods

I started my data collection by conducting epidemiological analysis of the clinical records to estimate the prevalence of diabetes and to understand the situation of diabetes amongst the Negev Bedouin. I conducted data analysis on the health records at the health centre. This delineated the number of patients with diabetes and gave some indication of the level of control and care.

Although Bedouin patients' records were computerised, a significant amount of data was missing from the records or was written in the wrong place. This led to difficulties in obtaining electronic reports when they were needed. As a result I had to review diabetic patients' records individually. I used SPSS for analysis of the data used chi square tests for significance and trends.

Qualitative methods

I used different types of qualitative methods in order to elicit and understand the beliefs and practices of Bedouin adults and health professionals regarding diabetes. I started my fieldwork with 42 sessions of non-participant observations conducted in the health centre and 18 in the outpatients' diabetes clinic (60 in totals), before going on to conduct 30 individual semi-structured interviews with Bedouin patients and 11 health professionals. Lastly I undertook 9 natural group household interviews (Beckerleg, 1997). Non-participant observation in these settings provided me with information about routine work in the clinic and the behaviour of patients and health professionals. Through semi-structured interviews I gathered data on patient beliefs, understandings, and their ideas and practices of self-management. I also gathered

data on health professionals' views concerning diabetes amongst the Bedouin and their clinical practices.

Natural group household interviews provided me with further data on the ideas held by members of the Bedouin community about diabetes (Murphy, Dingwall et al. 1998; Mays and Pope 2000). The natural group interviews took place among groups who were used to meeting outside of the research context. They provided me with community views about a range of topics, in comparison to focus group interviews which normally only form for specific interviews (Beckerleg et al. 1997).

Non -Participant Observation

Non-Participant observation is a way of allowing a researcher to collect data about a group of people in their real life setting (Pope & Mays, 1999, Wallace, 2005, Atkinson & Hammersley, 1998). The method allowed me to observe the ongoing routine work in the clinic, especially around the management of diabetes and other chronic diseases, as well the consultations between the patients and the nurses and physicians. Through observation, it was possible to learn about the nature of diabetes management, aspects of the professional patient encounters, types of questions patients were asking and explanations they were receiving, and the barriers the clinic faced in trying to bring diabetes under control (Free online library 2006). I carried out 42 observations between the hours of 8am and 1pm at the health centre over the course of 38 days and I observed 18 consultation sessions between the hours of 1pm and 5pm in the outpatient diabetic clinic in the district hospital over the course of 15 days.

My intention was to conduct non participant observation at the health centre in order that I could pay more attention to what was happening in the setting (Atkinson and Hammersley 1998 ; Labaree 2002), however I often found myself in a difficult position when health professionals or patients asked for my help as an interpreter when there were language difficulties. I refused to undertake any clinical role such as, for example, taking blood samples.

Carrying out non participant observation gave me the opportunity to see the daily reality of work and the dynamics in the centre (Wallace, 2005). I saw crowds of patients at the entrance to the health centre in the early morning waiting for the health professionals to arrive so that they could be examined and treated. I carried out my pilot study in the winter months and saw women with their children standing outside the clinic waiting in wet and cold weather with no shelter.

Table 6.1: Qualitative Data Set

	Health Centre	Outpatients Clinic
Days	37	12
Observing consultants	42	18
doctors	27	8
Nurses	15	7
Nutritionist	0	3
Interviews	39	5
doctors	3	3
Nurses	3	2
Nutritionist	0	1
Focus group interviews	1	0
with Health team		
Natural household group	9	0
interviews		

At both the Health Centre and the Hospital Clinic there were specific times for diabetic patients. In the health centre nurses mainly carried out quarterly reviews on Wednesdays. However nurses made appointments for patients on other days as well. For the outpatient diabetes clinic at the hospital, Bedouin patients had Mondays and Wednesdays afternoon as the Bedouin diabetes consultant had his sessions then. Usually the consultant had a list of 10-12 patients to review; however in practice only a few patients usually came, an average of between four and seven normally showed up.

When I observed consultations, I kept a low profile and did not talk voluntarily. I sat on one side with my notebook, watched the consultations and wrote notes in a way that did not disrupt the patients or the professional. This was fine until either the patient or the health professional started asked me to interpret which I only did after the consultation. I aimed to observe the appointment as it happened and indeed some of the patients did not look at me at all. They were used to observers as this health centre was used as a community training base for medical students. Other patients were surprised to see a Bedouin female sitting there as they were used to seeing Jewish students or Arab males.

During the health centre consultations with physicians I never observed a diabetic review, but I did observe consultations with diabetic patients who came for other conditions. I did however observe 15 diabetic patients being seen by nurses, and 18 reviews in the diabetes outpatient clinic seen by different health professionals.

These observations provided data on clinical encounters between professionals and Bedouins with diabetes. Observing these consultations between physicians and nurses with patients clarified the kind of information they provide, how patients expressed themselves concerning diabetes, the reasons they came to the clinic, how the physicians and nurses reacted and how they explained issues, and whether treatment was in line with clinical guidelines. This all contributed to eliciting information about routine professional practices and to building an understanding of diabetes care amongst the Bedouin community.

I planned to conduct two or three focus groups with health professionals. However I did not achieve this goal. In the health centre I tried to have one focus group in the weekly team meeting. However they did not have weekly meetings, the whole team met rarely, and usually it was only two or three of the team who would meet at lunch time. After more than two months, the team meeting was held where I was supposed to conduct the focus group. However as the manager and the head nurse used this hour to update the team about the health centre and the regional organisational news, I only ended up with half an hour. However, owing to issues of hierarchy, discussion was stifled. The head nurse started to answer the questions first and attacked and blamed the Bedouin for problems and she continued talking. The nurse was a strong personality in a key position and it was difficult for other members of the team to express other views. Despite this, a few professionals talked. I could not conduct a focus group with the specialist diabetes clinic in Soroka hospital as they did not have team meetings.

On reflection, it was clear that the health of Bedouin was a contested and sensitive topic, owing to their minority status, different lifestyle and wider Jewish-Arab relations within Israel. Therefore individual interviews were more appropriate for exploring the diversity of opinions which people were less willing to express in groups. I still needed health professionals' views about the diabetes situation amongst the Bedouin, so I conducted 11 semi structured interviews with them. I collected data from these interviews relating to professionals' understanding of diabetes amongst the Bedouin, such as causes, treatment, problems they face, the barriers between professionals and patients and their views and thoughts on how to tackle these issues. Chapter 5 draws on these interviews with health professionals, the observation of clinic sessions and the record review.

Semi-structured interviews with diabetic Bedouin patients

I conducted 30 semi-structured interviews with diabetic patients. The interview is one of the most common and important techniques that a researcher can use to elicit answers from participants about a particular issue (Green and Thorogood 2004; Taylor 2005). It is a meeting between an interviewer and interviewee whereby the interviewer aims to obtain details from the interviewee about his or her opinion, perceptions of meaning, and their understanding or experience on a specific subject. The interviewer should avoid imposing his or her own views or assumptions during the interview, thereby influencing the interviewee's opinion. The researcher should be open and flexible (Green and Thorogood 2004; Taylor 2005).

Originally I planned to interview only patients at the outpatient clinic who belonged to the health centre in which I was carrying out observations. However, professionals at the health centre told me they rarely referred patients to the outpatient clinic, and so I never came across any patients from the health centre at the hospital. Therefore I observed consultations with all the Bedouin who came, and interviewed the staff.

I conducted semi-structured interviews with 30 patients with diabetes at the health centre. I interviewed 20 women and 10 men as the percentage of diabetes was twice as high amongst women compared to men. The interviews provided data regarding beliefs about diabetes, knowledge, understandings, signs, complications, treatment, use of traditional medicine, and the causes of diabetes, which will be discussed in chapter 5.

It was difficult to tell who belonged to the village or to a tribal area. The majority of the diabetic patients whom I interviewed were from the town or the perimeter of the town where they lived in houses with electricity and water but were not yet recognised officially as part of the village. Essentially, dwelling type was more important for health and health care than administrative categorisation – that is whether people lived in houses with electricity and running water, unrecognised villages (shanty town dwellings) or in encampments in tents.

I interviewed fewer women from unrecognised villages and encampments, as the three women who refused to be interviewed were from outside the town. The reason

for this was because someone was waiting to drive them home and they had spent a long time at the health centre already (Anderson and Jack 1991).

Natural Focus Group Interviews

Focus groups are group interviews used to explore particular issues. They are ideal for exploring a set of questions or reflecting on common experiences (Kitzinger 2005). Usually the group has eight to twelve participants. The main goal of a focus group is to get a range of ideas and to understand different opinions. It is often utilised to determine how social knowledge about certain issues is generated and to capture the content of that knowledge. While the interviewer elicits responses, the observer does not participate directly in the procedure and can therefore concentrate more on actions and behaviour, and take notes. Topics can be explored through the diverse opinions being expressed (Pope and Mays 1999).

Natural group interviews are a type of focus group. The natural group interviews are composed of people who meet together outside of the interview or work together. Interviews of family members or health teams together, are examples of natural group interviews. The researcher in a natural group interview can note the reactions between participants, but there will also be a reaction between the participants and the interviewer ((Beckerleg, 1997, Green and Thorogood 2004).

I conducted household natural group interviews with a sub-sample of nine patients I met them at the health centre and asked their permission to visit. One of the natural group interviews was conducted in an encampment, two were on the perimeter of the village and the others were all in the village. This was because the majority of the

patients in the health centre were from the village, whilst the unrecognised shantytown villages had two GHS primary care clinics to cover them and one clinic from different (HMO).

I intended to conduct 15 natural group interviews, ten with women and five with men. I asked a Bedouin man with an MA degree who worked at Ben Gurion University to carry out the group interviews with men. He received a full explanation about the research and the topic guide for the interviews. He tried to organise these interviews a couple of times but was not successful. After a couple of months I felt nothing had been done. I asked another well-known Bedouin man who was working with a mobile health unit for the Bedouin. He agreed to conduct these interviews, however after a while he told me he could not organise any natural group interviews. The lack of group interviews with men is one of the limitations of this study.

Ten women who I met at the health centre agreed for me to visit their homes and discuss diabetes with other family members, relatives and neighbours. No one refused home visits; usually they welcomed me and invited me to come. They normally gave their family's mobile phone number and asked me to ring them a day or two before I was coming to give them time to tell other women about my visit. If they did not remember the mobile number, they said they would come again or send it with one of their relatives. In other instances we decided on a location and time in advance.

I usually coordinated my home visit with women I had met at the health centre. Usually a friend of mine, currently carrying out her master's degree at the local university and who had worked before as an interviewer, came with me on these visits as the note taker. I noticed after the first natural group interview that I could not both take notes and facilitate the group interview at the same time. I considered the first natural group interview as a pilot and took the note taker to the second interview. When I arrived at the house I was guided to the family room where I conducted the interview. The people who attended the meeting were the patient's family members such as daughters, daughters-in-law, mother, and sisters-in-law, as the culture is to gather when there is a visitor. Neighbours in some cases also attended as this usually happens when someone visits. Neighbours are usually extended family members as Bedouin live in extended family groups. The natural groups usually contained five to ten participants, but that number was constantly changing as women came and left.

Positionality and Reflexivity in the field

Researching at home I was an insider the community as a Bedouin and an outsider as a nurse and PhD student who had been living abroad. For the health staff I was an insider as a nurse but an outsider as a Bedouin. This meant that I had to negotiate the spaces and the practices of reflexivity taking into consideration my positionality and relations in the community in different levels (Sultana, 2007, Nagar 2002).

Positionality inside the health team or how I appeared to health professionals staff (Al-Makhamreh and Lewando-Hundt 2008) was one of the issues that I had to deal

with throughout my fieldwork . As I used to work before in the same health care organisation but in a different area, some of them knew me and other had heard about me When the clinic was busy at certain times, made some members of the team saw me to as a potential extra team member the clinic and expected me to help in dealing with answer patient queries or taking blood. When this happened, I confirmed that I was an observer as part of my research. Despite my repeated explanations, the staff continued to see me as a pair of extra professional hands and kept asking for my involvement saying ‘‘You know the Bedouin sector and what to do! (At makera et amigzar habedui, ve ma osim). My refusal clearly was unsatisfactory and generated tension particularly with the head nurse. A difficult instance was observing a consultation with a diabetic patient appointment and the doctor, and the doctor asked me to calm the patient and act as an interpreter by translating into Arabic what he wanted to say in Hebrew to her and her response in Arabic into Hebrew. I told the patient that the doctor was going to talk with her and then told the doctor that I could only observe. I kept myself and the chair I was sitting on, further and further away from both of them until I was observing from a corner of the room. These requests and my repeated refusals were a difficult aspect of the fieldwork in the clinic. They saw me primarily as a fellow health professional and I had to keep reasserting my position as a researcher. I refused to give medications, inhalation or take blood samples and did not act as an interpreter. This was essential in order to observe the clinic encounters.

I felt conflicted and this situation presented me with ethical dilemmas because if I had interpreted, the patient would have had a better consultation and understanding

of her condition. Similarly, observing nurses doing inadequate follow-up was also frustrating. I had to foreground my role as a researcher both for them and myself. As a nurse, I was surprised at the lack of comprehensive explanation and time spent with patients. My gaze as a researcher was more critical of everyday practices and behaviour in the clinic than when I was working in this setting as nurse. For example, I found that some of the Jewish staff had no knowledge of Arabic or Bedouin culture and lifestyle. Whilst working before in this setting as a nurse, I had never asked if my colleagues had any linguistic or cultural training for working in the clinics serving the Bedouin as I had been focused then on my clinical work.

My positionality as an unmarried Bedouin woman researching her own society was complicated. As Bedouin woman I needed to behave acting according to Bedouin cultural norms and expectations. When I started my data collection patients saw me as a stranger as I was not part of the health care team and I was not wearing uniform. They asked the team members about me – questions such as: Who was I?, What was I doing there?, To which tribe did I belong? and Was I married or not? All these speculations arose because I was a Bedouin woman and my role in the clinic was unclear (Järviluoma, Moisala et al. 2003 ; Kosygina 2005).

Some were suspicious about me and my role, especially as I came to reception to ask about diabetic patients that were due to come that day. Also I sat down in the corridor to observe people who were waiting, and some even thought I was a disreputable woman who was hanging about in the clinic and talking to unrelated men. Women were more suspicious of me than men and they started to talk to others about me. Some of them approached me and asked me what I was doing at the clinic

especially as I was not working with the team. This was understandable. If I had been in the clinics that my tribe use, everyone would have known me but then my positionality as an observer and researcher would have been untenable. If I had been wearing a uniform, there would have been no questions. Their queries and my explanations meant that my position as a researcher was clarified and known in the clinic and community during the six months I was there. My research was not covert. I understood their concerns owing to being an insider as women are not allowed to be seen walking or sitting in public spaces without understanding the reasons.

I followed a conservative dress code wearing a long monochrome coloured outer dress (jilbab) which reflected my status as an unmarried woman and I covered my head with a dark headscarf. I avoided floral patterns and the colour red both of which would signify less respectability.

In one event, a woman I was interviewing started to cry and asked me to forgive her. I did not understand why she was crying in the beginning and thought she had a problem. After she calmed down, she told me that when she saw me the first time, I was talking to a man from her tribe. She thought I was a bad woman coming to the clinic. She shared her opinion with other ladies and they agreed. She then added 'I know now that you are a researcher and you are a modest woman'.

In another case, a young man saw me leaving the doctor's room, and after a couple of days he came and tried to talk to me in a different way. I kept my professional performance act according to ethic codes. When he asked me personal questions I

refused to answer and I explained that I was carrying out research. He went to the Bedouin doctor asked about me and my role in the clinic. When the doctor asked him why he was interested, he told the doctor he was interested in marrying me and it was important to know my family and my tribal affiliation.

Bedouin men and women with diabetes saw me as a person who understood their culture and language and approached me for help outside and inside the clinic. However, because I was a member of a different family and tribe, they may have been reluctant to share problems with me as it is forbidden to tell someone not from the family about your family situation. However, it is acceptable to confide in a health professional. Initially I did not reveal I was a nurse, introducing myself as a researcher. However, if they asked me about my work before I was a researcher, then I told them I had worked as a nurse in another clinic area.

Though I am Bedouin and belong to the same community, some patients saw me as an outsider. In many cases people came to ask me to help them or to give them a further explanation of the doctor's instructions. I would just repeat what he had said. Others asked me to tell the doctor about their complaints and I had to refuse to do this. My position as a researcher was thus unsatisfactory for the health staff, the Bedouin patients and myself and it was only feasible because it was sustained for a limited period of fieldwork.

In the household natural group interviews, the Bedouin women treated me as a respectable visitor which they should accept with generous hospitality. I found it very difficult to say all the time that I came only to talk with them not as a normal

visitor. I heard sentences such as *'You are Bedouin and know how we should receive our visitors'*, *'We prepare a small thing which is not in line with your status'*.

Usually the time of the natural group was agreed with the interviewee in the clinic, and I called day before the meetings to make sure she was going to be at home.

When I arrived they were waiting, the woman with other women which she had invited. Often, food was prepared, cooked meals, purchased soft drinks, cakes and refreshments, tea and coffee. On one occasion a man came and said he wanted to slaughter an animal to mark my visit, because he knew my father. I convinced him to not do that and used certain Bedouin words avoid giving offence and made him feel that he could respect me and my father in ways other than slaughtering a sheep.

The women were interested to know about me and how I came to be studying abroad, and about my family and were less interested in the research topic. The elderly women told me that studying abroad was so difficult and that my family was unusual in letting me travel without a man. The younger women praised me and showed their admiration.

It was fascinating for me to do fieldwork outside the clinic; I felt women talked more freely about the services, the health team and criticised them. As an unmarried Bedouin woman I never have the opportunity to visit other families and tribes to sit and talk freely with women. I was limited in my movement and not allowed to visit other family without my family accompanying me which usually occurred on certain occasions such as weddings. Whilst I was working as a nurse prior to this research and even during the interviews at the clinic women were less relaxed and open about what they thought and how they dealt with their illness. The information that I

elicited in the natural group interviews was more comprehensive and with a wide range of opinions from women of different ages.

In the diabetic outpatient clinic the dynamics were different as most the health team there knew me before and I had worked with them. They showed more respect and understanding toward what I was doing. They expressed many times that they needed research and community based interventions programmes to tackle diabetes amongst the Bedouin.

I felt supported and free to observe without having to pay much attention or consideration to the dynamics of the team and how my presence would affect them. In the outpatient clinic it was the first time they talked about diabetes amongst the Bedouin community as an epidemic the need for a community based comprehensive health programme

Conclusions

In this chapter I have discussed the methodology and the methods adopted for the research study. The research is a case study about diabetes amongst Bedouin in the Negev. It combined quantitative and qualitative methods in order to widen the understanding of the treatment, control and experience of diabetes. I started my fieldwork with a pilot study to practice and explore my interview guideline questions. Then I collected data from electronic records which I used primarily for quantitative analysis (chapter 4). I used a combination of several qualitative methods to investigate patients and professionals lay encounters and views on diabetes. I started my fieldwork with non-participant observations in the Health

Centre and Out-patient Diabetes Clinic, to look at the overall management of diabetes and the behaviour of patients. I conducted individual interviews with patients and professionals to explore their understanding, lay beliefs and opinions regarding diabetes and diabetes management. I managed to carry out one focus group amongst the health centre team to discuss the Bedouin diabetes situation and assess their views about the situation. Lastly, I carried out natural household interviews with the women; however I could not interview men as I failed to find an appropriate trained male to do so. During the fieldwork I was aware and open about making changes and carefully watched the setting. For example, when I found out that the professional's perspective was not being expressed in a group interview I decided to carry out individual interviews.

As a female researcher studying my own society, and as a trained health professional who had worked in similar clinics for the same HMO, I was aware of my own positionality and adopted a reflexive approach to my fieldwork which has been elaborated in this chapter.

The next two findings chapters will set out the analysis of the findings of the study. Chapter 4 is an analysis of aspects of health care provision using the right to health conceptual framework. Chapter 5 is an analysis of how lay and professional explanatory models of diabetes and experiences of living with diabetes can be framed and linked to the materialist and socio-behavioural explanations of health inequalities. In conclusions Chapter 6 presents the conclusions of this study in relation to the Negev Bedouin, Bedouin in the Arab world and indigenous peoples elsewhere both empirically and conceptually.

Chapter 4

Rights to Health Care

This chapter addresses the following research question:

To what extent can a rights based approach in terms of quality availability, accessibility and acceptability extend understandings of health and health care provision to marginalised Bedouin in the Negev, Israel who have diabetes?

The chapter is based on the components of a rights based approach as set out in UN General Comment 14 in relation to the Availability, Accessibility, Acceptability and Quality of health care provision. The chapter will analyse and discuss in the following order, the quality, availability, accessibility and acceptability of health care provision to Bedouin in the Negev with diabetes drawing on the data from non-participant observation in the clinics and interviews with health professionals and Bedouin patients and their family members.

Right to Health

The UN general comment 14 (2000) stated that the health is a fundamental human right which every human being is entitled to enjoy to the highest standards. It defines four essential elements availability, accessibility, acceptability and quality (AAAQ). The availability highlights the health care facilities, goods and services

including the underlying determinants of health such as safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and trained staff. It also includes developing preventive and curative care by the State in terms of what is reasonable within the resources available medically appropriate and in good quality and skilled health professionals and appropriate equipment. Accessibility involves the health facilities and services being accessible to everyone without discrimination.. It includes physical, economic, non-discriminatory in terms of care and information.

Acceptability is defined as all health facilities, goods and services being provided in a way that respects the cultures of, minorities, peoples and communities, and should be sensitive to aspects of gender, age and disability. Quality of provision is health care provision in terms of facilities, equipment, and care that meet benchmarked standards.

Aspects of Quality of Care

This analysis of the quality of care was based on observation of clinic sessions in the Health Centre and the Hospital Outpatient Diabetes Clinic supplemented by interviews with staff and patients. It is not an assessment of the clinical competence of individual staff but rather of day to day practice.

There were some problems with aspects of the routine care of patients with diabetes regarding the quality of the medical records, nurse work routines, and a lack of clear protocols and guidelines for diabetes care. This meant that it was difficult to estimate

the prevalence of diabetes and aspects of the treatment being given to the population using the Health Centre.

Medical Records

The patients' records were obtained electronically as records were computerised. However, many of the diabetic patients' records were neither updated nor complete. Physicians and nurses wrote their comments and test results in different places in the patients' files and the information was not always available on the electronic records. For instance, the electronic report showed that only one eye test had been conducted the previous year, despite the fact that the optometrist came every two weeks to the Health Centre and was seeing diabetic patients on these occasions. I met the optometrist twice and clarified with the clerical staff that they made appointments for diabetic patients for eye tests. Indeed, from my observations at the clinic, along with the interviews I conducted, it seemed that most of the diabetes patients had seen the optometrist during the last year.

Another confusing issue regarding recording patients' data occurred amongst the nurses. Each of the two nurses dealing with the diabetic patients had a list of patients in a notebook. They wrote down patients' demographic details, type of medication, and appointments. The lists were not consistent in terms of how data was recorded and checked. One of the nurses viewed diet as a type of treatment and recorded patients with diet as treatment, whilst the second nurse's book had no record of diet in this way.

Physicians and nurses had two different computer programmes for dealing with patient data. One was called 'Clicks' which contained patient files which the doctors and nurses used for recording diagnoses, visits, medications and blood tests. The other was called 'Ofek' where external medical data could be obtained such as appointments with consultants at the local hospital and examinations such as ultrasounds and X-rays. I searched in both programmes to find referrals to the specialist diabetic outpatient clinic in the hospital. I noticed several referral letters to the diabetic specialist clinic in the hospital, though whether the patients attended these appointments was not recorded.

I identified 148 diabetic patients - 51 men and 97 women - from the medical records and nurses notes in the health centre. There was a significant amount of missing data from the records, such as BMI, height, optometry screening and referrals. The BMI of 62 patients was missing. There were no height measurements at all, and only one report of an optometry screening. Six patients were recorded as being referred to a diabetes consultant, 17 patients were not reviewed by a nurse in the previous year, and the type of medication for 13 patients was missing. However, age, sex, weight, glucose, lipid levels, kidney functions, time of diagnosis and treatment were recorded in over 90% of the patients' records.

Table 4.1: Summary of combined data from 148 diabetic patients' records taken from Clicks and Ofek computer programmes

Variable	Valid data N	Valid data %
Sex	148	100%
Age	148	100%
BMI	86	58.1
Weight	136	91.9
Glucose	139	93.9
HbA1c	144	97.3
LDL	138	93.2
TG	140	94.6
Creatinine	135	91.2
BPS	140	94.6
BPD	140	94.6
Treatment	135	92.2
Nurse review	131	88.5
Fundus	1	0.7
Kidney	146	98.6
Specialist diabetic clinic	6	4.1
Eye clinic	1	0.7
Years with diabetes	146	98.6
Date of Diagnosis	146	98.6

Diabetic Patient records

70% (92) of diabetic patients had been reviewed by nurses 2-3 times in the last year and 12% (17) were not reviewed. According to the normal protocols, a nurse should review a diabetic patient once every three months if his medical measurements are in the normal range.

HbA1c is one of the main measurements which demonstrate well controlled diabetes, and according to the International Diabetes Federation (IDF), well controlled diabetic patients have HbA1c of less than 6.5. Only 29 (20%) out of 148

patients had diabetes under control, according to this measure. The majority of patients were treated by oral medication; with more women having a combination of oral medication and insulin injections.

Cohen et al, (2005), reported that among Negev Bedouin with type 2 diabetes, only 1.7% registered with CHS were treated with diet controls, compared with 2.1% of Jews in the Negev. However, I found that 3.7% patients in the health centre were being treated through diet control. According to the same paper 7.7% of Bedouin and 7.4% of Jews were being treated with Insulin, compared with the 3.7% which I found in the Health Centre. Cohen et al (2005) found that 6.1% of Bedouin and 6.4% of Jews were treated with a combination of tablets and insulin; in contrast I found 16.3% of Bedouin were treated with this combination in the Health Centre.

Table 4.2: Comparison of treatment types between the study Health Centre and Bedouin, and Jews in the Negev district

		Own data	Cohen et al data	
		% of patients in Health Centre	% of patients in Bedouin*	% of patients in Jews*
Treatment	Diet	3.7	1.7	2.1
	Tablets	76.3	84.4	84.1
	Insulin	3.7	7.7	7.4
	Tab+ Ins	16.3	6.1	6.4

* *Bedouin and Jews registered with CHS in the Negev district.*

Source: Cohen et al (2005)" Diabetes control in the Bedouin population in Southern Israel". Medical Science Monitor, 11(8):CR376-80.

The study by Cohen et al (2005) has some serious shortcomings. The population denominator used to calculate these percentages was not clear. The study stated

clearly that there were 120,000 Bedouin people living in the Negev, and that the majority of them were registered with General Health Services, though the exact number was not mentioned.

The population was classified as those living in recognized towns or tribal areas but it was unclear how they knew, from the electronic records, which patient lived in a recognized town or in a tribal area. There were fewer clinics in the tribal areas- which have unrecognised villages- however people living in tribal areas may be registered in clinics in nearby villages. For example, in this study, the Health Centre had many patients registered who lived in the tribal areas (there is no way to know the percentage from the electronic file). The centre staff found it difficult to estimate their number.

The basis for the estimation of the prevalence of diabetes is not obvious, as the denominator is not known. According to my conversation with the head nurse of the Southern Region in the General Health Services, it is difficult to separate the Bedouin and Jews patients' data since clinics in the Jewish towns of Beer-Sheba, Dimona and Arad serve both groups. All citizens in Israel have an identity card number (ID) from birth or migration. All patients in Israel are registered with a health clinic by their ID number. There is no way of knowing if someone is a Bedouin or a Jew by their ID number so it is not possible to establish how many Bedouin are registered in clinics which serve both population groups in the cities or in collective farms (kibbutzim).

The same concern was raised by a diabetic consultant in the diabetes outpatient clinic at the hospital. She believed that the prevalence of diabetes was higher than all the health provider’s estimates.

“Today it’s simply an epidemic. The prevalence [of diabetes] amongst Bedouin is higher than all of the GHS and Younes et al’s [2000] estimates” (consultant - personal communication)

Table 4.3: Comparison of women and men by annual records review, level of control (HbA1c) and type of the medicine

		Men	%	Women	%	Total	%	PV
Records reviewed annually	once	5	11.6	12	13.6	17	13	0.23
	2-3 times	34	79.1	58	65.9	92	70.2	
	4-5 times	4	9.3	18	20.5	22	16.8	
	total	43	100	88	100	131	100	
Level of control	<6.5	8	15.7	21	22.4	29	20.1	0.32
	>6.5	43	84.3	72	77.6	115	79.9	
	total	51	100	93	100	144	100	

Estimated Prevalence of Diabetes in the Health Centre

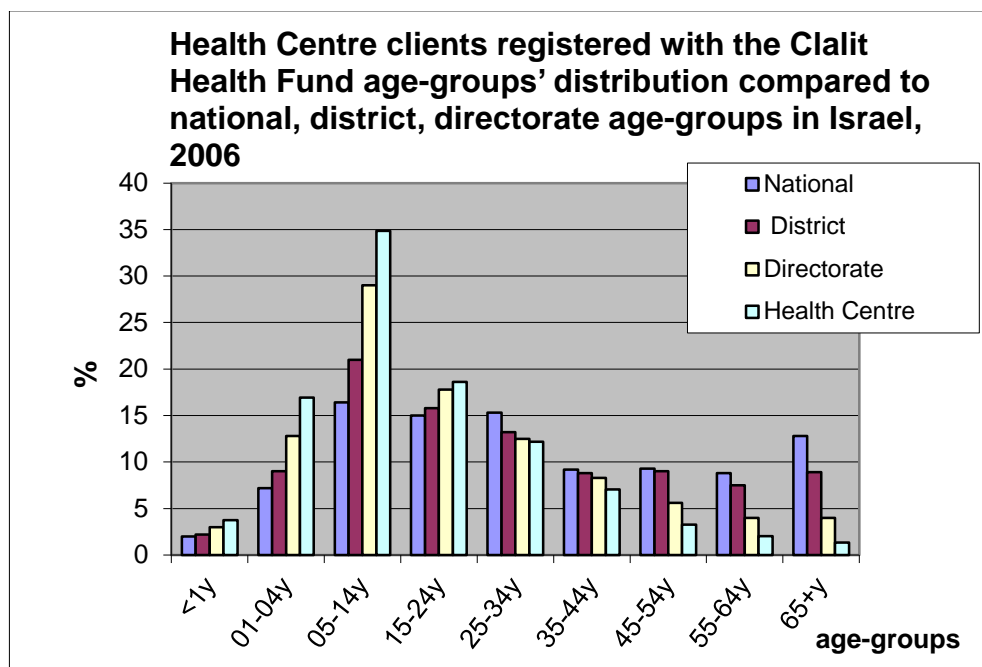
In order to establish a more accurate estimate of the prevalence of diabetes, I used three sources of data, my own data collection, health centre records and the study of Cohen et al (2005).

According to the health centre data there were 7300 patients registered at the health centre. The health centre served the whole area including the two GHS clinics, one of which was inside the recognized village and the other in the tribe close to it. The health centre and the other two clinics of GHS provided health care to approximately

14000 registered patients. Every patient had their own GP, and other GPs would see patients if their clinics were closed or their GP absent.

A clinic report obtained from the clinic’s computer programme sifted through all 14000 patients and selected only the patients registered with GPs in the same health centre. I received a graph from the health centre manager, showing the percentages of registered patients in each age group. From this graph I calculated the number of registered patients in each age group.

Table 4.4: Age-group distribution of health centre clients registered with the Clalit Health Fund, compared to national, district, directorate age-groups in Israel, 2006.



Source: Health Centre presentation 2006.

From data I had collected I obtained the number of patients in each age group, from that I calculated the percentages of diabetic patients in each age group. Graph 7 shows the prevalence of diabetes in each age group in the health centre. For

example, 39% of people aged 55-64 had diabetes. If one compared the Bedouin and Jewish populations living in the southern district registered with GHS, the prevalence of diabetes amongst the group aged 34 to 64 was higher, and the prevalence of diabetes was higher amongst Bedouin compared to Jews.

This shows that the estimate of diabetes prevalence made by the Health Centre was higher than that estimated by Cohen et al (2005) which was calculated less accurately.

Table 4.5: Prevalence of diabetes amongst patients registered in the Health Centre divided into age groups. Comparing my own data with Cohen et al (2005)

					Prevalence of diabetes in southern district*	
Own data					Cohen et al data	
Age groups	% patients in H.C	Number of people	Total Number	Health Centre	Bedouin*	non Bedouin*
25-34	12.17	888	4	4.5/1000	7/1000*	5/1000*
35-44	7.06	515	27	52/1000	38/1000*	16/1000*
45-54	3.26	238	38	160/1000	111/1000*	51/1000*
55-64	2.02	147	58	390/1000	191/1000*	122/1000*
65+	1.33	97	21	210/1000	218/1000*	203/1000*

Source: Cohen et al (2005)"Diabetes control in the Bedouin population in Southern Israel", Medical science monitor, 11(8):CR376-80.

This section was collected with primary records analysis. It discusses the data obtained and analysed from health centre records. It points out the lack of information in the electronic records which made it difficult to obtain straightforward reports from the computer programme. It also showed the missing data.

Clinical guidelines practice and implementation

During my fieldwork in the Negev I was unable to find guidelines issued to doctors and nurses to use in their practical work in the General Health Services (GHS).

Searching the GHS website I only found that the Family Medicine Department of the northern district of GHS had put diabetes clinical guidelines on its website. The website contained a link to the latest version of American Diabetes Association (ADA) clinical guidelines, published in January 2008. The name of the link is "Standard Medical Care in Diabetes".

<http://www.emekmed.com/contents/page.asp?contentPageID=91&contentCatID=3>

These guidelines are written for American health professionals working in primary health care. No changes had been made to the guidelines to adapt them to the Israeli population in general or to the Bedouin in particular. Some components that the health professionals should follow according to guidelines of treatment were not applicable in practice to the Bedouin population. For example, the recommendations to empower patients to make them feel confident to change their treatment dose according to their social and physical activities, which the guidelines provided in depth information for, were not adjusted for a Mediterranean, Israeli or Arab society. Similarly the nutritional recommendations related to nutrition were very general and not adapted.

The guidelines provided extensive detail on the criteria for classification of types of diabetes, prevention, screening and testing. The document also contained a comprehensive explanation of the components of "Diabetes Care" which should

have been evaluated by the clinical team annually (see Table 4.9), emphasizing that a management plan should be formulated individually for each patient according to his or her condition, and characteristics. The importance of glycemic control is emphasised and includes two vital keys for glycemic control, patient self-monitoring of blood glucose (SMBG) and HbA1c.

Table 4.6: Components of the comprehensive diabetes evaluation

<p>Medical history</p> <ul style="list-style-type: none">● Age and characteristics of onset of diabetes (e.g., DKA, asymptomatic laboratory finding)● Eating patterns, nutritional status, and weight history; growth and development in children and adolescents● Diabetes education history● Review of previous treatment regimens and response to therapy (A1C records)● Current treatment of diabetes, including medications, meal plan, physical activity patterns, and results of glucose monitoring and patient's use of data● DKA frequency, severity, and cause● Hypoglycemic episodes● Hypoglycemia awareness● Any severe hypoglycemia: frequency and cause● History of diabetes-related complications● Microvascular: retinopathy, nephropathy, neuropathy (sensory, including history of foot lesions; autonomic, including sexual dysfunction and gastroparesis)● Macrovascular: CHD, cerebrovascular disease, PAD

- Other: psychosocial problems,* dental disease*

Physical examination

- Height, weight, BMI
- Blood pressure determination, including orthostatic measurements when indicated
- Fundoscopic examination*
- Thyroid palpation
- Skin examination (for acanthosis nigricans and insulin injection sites)
- Comprehensive foot examination:
 - Inspection
 - Palpation of dorsalis pedis and posterior tibial pulses
 - Presence/absence of patellar and Achilles reflexes
 - Determination of proprioception, vibration, and monofilament sensation

Laboratory evaluation

- A1C, if results not available within past 2–3 months

If not performed/available within past year:

- Fasting lipid profile, including total, LDL, and HDL cholesterol and triglycerides
- Liver function tests
- Test for urine albumin excretion with spot urine albumin-to-creatinine ratio
- Serum creatinine and calculated GFR
- Thyroid-stimulating hormone in type 1 diabetes, dyslipidemia or women over age 50

Referrals

- Annual dilated eye exam
- Family planning for women of reproductive age
- Registered dietitian for MNT
- Diabetes self-management education
- Dental examination

- Mental health professional, if needed

*See appropriate referrals for these categories

Source: American Diabetes Association (2008) "Standards of Medical Care in Diabetes-2008".

I asked the nurse in charge of the Health Centre if they had clinical guidelines for diabetes in the clinics. She answered that they had and she would show them to me when she had time. After two weeks she showed me an internal letter from the GHS Southern district which contained guidelines to be followed by nurses when treating a patient newly diagnosed with diabetes. This letter was in a folder in her room and I am not sure if other nurses had a copy of it. It was a two page document setting out a strategy of four meetings with a new diabetic patient. These meetings were intended to empower the patient and give them information and explanations about the disease, treatment, diet and physical activity.

According to the document, the first meeting should deal with getting to know the patient, reaching an agreement about health care, including allowing the patient to choose the staff that are going to treat him or her, giving the patient a basic knowledge of diabetes and discussing the type of treatment. The aim of the second meeting should be to build an individual care plan, which is suitable for the patient's needs and daily life, and should be acceptable to the health team and the patient.

Both sides should agree the treatment plan. The aim of the third meeting should be to implement the health care plan, adjust it to the patients' needs, and check the patients' understanding of the plan. The aim of the fourth meeting should be to reach

an agreement between the patient and the health care team about the final health care plan. Therefore this was a structured way of developing a health plan rather than treatment guidelines.

Daily routine work of clinic nurses and the quality of diabetes reviews

The Health Centre opened 5 days a week at 8am – 4pm and on Fridays from 8am – 12pm. The work routine in the Health Centre was that diabetic patients could be reviewed by a nurse only after 10:00am as at morning the three nurses were busy taking blood tests and seeing emergency conditions that family doctors and paediatricians referred. For example, patients with asthma who needed oxygen saturation and inhalation, or children with high temperatures would be provided with immediate care. Therefore diabetic patients were reviewed only after the nurses' had finished taking blood tests and the first busy two hours were over. This meant that diabetic patient needed to stay in fasting until the nurses took blood glucose from their fingers. This would make them feel unwell and they would complain about low blood glucose symptoms such as dizziness, headaches and tiredness.

'My appointment is at 10.30, I come with my son who teaches at a school near the clinic, I come at 7.30 when I am fasting for my glucose blood test, already I have a headache and feel dizzy' (Married woman, 64, interview 14).

The nurses daily work routine was the health team's decision as not all health Centre worked in this way. From my previous clinical experience prior to this research, I knew that in some other clinics and Health Centres the nurses would divide the work between them which allowed one of them to start seeing diabetic patients from 8:00 rather than 10:00 so that their fasting was for less time.

Most of the diabetic patients that I observed having a check-up came without an appointment, and some did not have their appointment card which the staff and the patients called a green card, after the colour of the card. The nurse's review should take between 20- 30 minutes, however if the nurse carried out the review between taking blood tests early in the morning, it took less than five minutes.

'The patient knocked on the door several times and the nurse kept telling her "I will see her after 10.00". The nurse checked first whether there was anyone waiting for a blood test and then she let the diabetic patient come in. She checked her blood glucose and blood pressure and asked her about the green card which she did not have. The nurse made a new one and wrote an appointment for three months time... A patient came in for a blood test and the nurse stopped the review' (observation on 05.09.07).

During a routine review the nurses reviewed the glucose blood test, and measured blood pressure. Sometimes they checked their feet, and in a couple of cases touched their feet to see if there were any wounds or ulcers, to check their sensitivity and to check if they could feel a pulse. They also weighed some patients. They clarified with them the last time they saw the optometrist. If they said more than a year ago

then the patient would be referred to the clerk's office to make an appointment to do so.

'As the nurse went through the computer programme she asked the patients about when she had last done ECG, the last time she saw an optometrist, and the last time she had had a mammogram. The patient told her she had an ECG a few months ago, saw the optometrist last year and that the doctor had referred her for mammogram but she was still waiting for the appointment' (observation on 03.09.07).

During my 42 observations with doctors and nurses in the Health Centre I did not see any patient bring their self-assessed readings to the nurse. Usually the patients had their appointments in the morning. They arrived early, fasting, and waited for the nurse's review. Some of them had blood tests or brought urine tests the same day. As they were fasting they could not wait long for their reviews, as they needed to take their medication and eat. So they kept knocking on the nurse's door, asking her for a review. Usually the nurses let them come in between blood test appointments. They would take blood glucose, blood pressure; ask them if they had done an ECG and whether they had seen the optometrist in the last year. They would also ask women over 50 when the last time was that they had had a mammogram. Then the nurses would make a new appointment for three months time. I observed seven reviews when the blood glucose level was high (more than 15 mmol/L) and the nurse continued the regular routine and asked. Not every diabetic patient came when they had an appointment. Some of them would ask the nurse to check their glucose levels even if they had a review the previous month. Others had had their

last reviews a long time ago. Some would be in the clinic for other reasons, such as accompanying another family member and using the opportunity to have a glucose test. Patients were mainly concerned about the result of the blood glucose test and less about other aspects of the review. They certainly asked the nurse to do a blood glucose test if she insisted on only seeing them within their appointment time.

According to the Health Centre team all patients had their own glucose testing machines, however only a few ever carried out glucose blood tests at home.

According to the patients not everyone had a machine for self-testing glucose.

'I did not come to the meeting for diabetic patients last year so I don't have one' (Married woman, 55, interview 4).

They explained that the Health Centre had given out the machines when they attended a 'Diabetes Day' when patients received a lecture about the disease, diet and exercise. Patients who had machines gave different explanations of why they didn't monitor their glucose level at home and bring the readings to the nurse. An old lady told me that the person who was trained to do it did not live in the same household and it was difficult to go and ask them to do it. Others told me they were scared of the result especially when they knew it was high. Others preferred to come to the nurse, and thought they would know how to interpret the results better than their family members.

'I felt bad last night, I did not check my blood glucose because I knew it was high, I know myself well. When it is high I feel bad and just want to sleep' (Widow, 58, interview 3).

During the consultation sessions I observed patients with their family doctor, I saw that patients in general came for monthly prescriptions or for other health conditions. I did not see any doctor reviewing diabetic patients as this was part of the routine work of the nurses. However - perhaps because I was present - the doctor tended to ask patients about their diabetes in terms of whether they were taking their medication or drinking tea with or without sugar. In many cases even if patients wanted to talk more, the physician was in a hurry and mentioned that many patients were waiting outside the door and sometimes even knocking.

The number of patients, their behaviour and demands made it difficult for the health professionals to give them comprehensive care, to fully explore their situation and adequately review the condition of their chronic disease. Almost all the patients that visited the clinic during the day were present from early in the morning, even before the clinic opened. This situation put the team under pressure so that they would try to minimize the waiting time in the clinic and this affected the quality of treatment in a negative way. (In addition there were language difficulties which will be discussed in the section on accessibility and acceptability in this chapter).

There was no consensus amongst health professionals concerning the situation of diabetes amongst the Bedouin. Some members of the health centre team thought that the diabetes situation was improving and would improve in the coming years because the older generation would die and would be replaced with younger more educated patients who would take better care of their illness.

'In 20 years the situation will be better as people will be better educated, they will know more, and understand more. They hear about experiments. It is a slow process and will come naturally with time' (Clinic nurse, T).

Others believed that the situation will worsen since they believed the Bedouin do not adhere to doctors' recommendations. There was also a group which thought that the prevalence would increase and the situation would deteriorate as a result of complications of the disease.

'If we leave the situation as it is now, it means every Arab child born in Israel will have a 50-60% risk of becoming a diabetic. And this will mean that for the first time we will have a decrease in life expectancy and dramatic morbidity' (specialist doctor, Dr A).

'Today it's simply an epidemic. Today the prevalence amongst Bedouin is higher than amongst Jews' (specialist doctor, Dr B).

'From my long experience with the Bedouin community, the problem is just increasing; there are more and more patients' (diabetes Nurse X).

At the Health Centre the doctors gave different explanations for the reasons that diabetes was not under control. One of the family doctors, who had half of the diabetic patients under his care, claimed that the reason for the high levels of diabetes were that patients did not take their medications as they were instructed.

'First of all tradition disrupts the treatment in the Bedouin community. I have a new computer programme. Using it, I can see if they have bought

their medications or not and can see whether they bought it since the last time I prescribed it. In the past when I asked them if they were taking their medication and they said yes I knew they were lying to me. Now I can see when they purchase the medication' (Clinic doctor, Dr C).

Some health professionals insisted in their interviews that the problem lay with the Bedouin community. They mentioned more than once that they were doing their utmost but the Bedouin were not adhering to their advice.

'The problem is not us, it is their problem' (Clinic doctor, Dr C).

'As I said the problem is not with the doctor. The doctor gives comprehensive explanations. The patient knows what he should eat and what he shouldn't, what he is allowed and what he is not.' (Clinic Bedouin doctor, Dr D).

'Diabetes control in the Bedouin is like stocks and shares, some patients' diabetes is well controlled some not...some will never be controlled' (Clinic doctor, Dr C).

However sometimes they mentioned that they did not have enough time to do appropriate reviews.

'We don't have time... I asked the clinic office to give us two hours but they refuse and in the staff meeting the idea was rejected' (Clinic Bedouin doctor, Dr D).

Some of the health professionals thought there was little effort made both by the clinic teams and the general health services to change the situation or deal with it in an effective way.

'We have two problems; firstly, the professionals don't make efforts to change the situation. We should train them so what when they see a patient with high blood glucose for example 300, they should take the situation seriously and not send them home with the next appointment in three months' time. This is malpractice. It's like if you see a patient with chest pain and send him home. A diabetic patient will be blind in five years... The second is that the professionals don't care. When patients see a doctor who is concerned about their situation they will take more care' (Diabetic nurse, Hospital outpatient clinic).

'Also there is the idea amongst the professionals that with Bedouin there is nothing which can be done for them: Bedouin do not come to their follow-up appointments, do not care about their diabetes, they don't come to appointments, because of that we will give minimum care' (Specialist doctor, Hospital Outpatient clinic).

In conclusion when assessing the quality of care being given to diabetic Bedouin patients, it would seem that there are issues with clinic routine care in terms of medical record keeping, the timing and length of consultations and reviews, and a general view amongst the professionals that the patients do not adhere to treatment regimens despite being given comprehensive care and that this is their fault.

However, the care is compromised by issues of availability, accessibility and acceptability which will be explored in the following sections.

Availability of Health Care

Overall, within in Israel as explained in Chapter 2, there is national health care provision supported by a national insurance scheme. This means that primary secondary and tertiary care is available to all. However, the amount of provision varies depending on the location of the population and their ethnicity. As elsewhere in the world, health care provision is often more available in cities rather than in rural locations where the population is dispersed (Boutayeb and Helmert 2011, Hartley 2004) and the Bedouin in the Negev fall into this latter category.

As explained in chapter 2, there are four Health Providers and the majority of Bedouin are registered with CHS the main provider to the Bedouin and to the rest of the population. It also owns hospitals including the one in Beer-Sheva, the Soroka Medical Centre serving the region.

In the Negev, amongst Bedouin recognised and unrecognised villages, there are 30 primary care clinics of which 7 are comprehensive health centres with more facilities all providing curative care for when people are sick (Gross et al, 2001). There are 15 MOH preventive care clinics providing antenatal care and immunization of babies. These are located both within the recognised towns and villages and unrecognised villages however there are better equipped clinics in the former with more infrastructure in terms of buildings and facilities. Although the Bedouin population has an age structure that is young (50% under 12) with a high birth rate there are less

doctors and nurses per capita than in the Jewish rural settlements as set out in Chapter 2.

Health services in the form of clinics are available within the Bedouin towns and villages but vary. The services are more limited within the unrecognised villages in terms of hours, staffing, and facilities. A few types of medical consultants – gynaecologists, ophthalmologist and paediatrician - visited the clinics in the Bedouin community clinics. Patients in the region needed to travel to Beer-Sheva for secondary specialist care at outpatient clinics or for hospitalization for illness or childbirth. In some of the comprehensive health centres, a paediatrician was part of the core team, and at others there was a paediatrician one or two days a week. Pharmacies varied in size and content. In the comprehensive health centres in the Bedouin recognised villages and the town of Rahat, such as the one where I was based during this research, there are pharmacist teams and almost all type of medications available, however in the small clinics the medications were more limited and the nurse was usually in charge of dispensing the prescriptions. This often happened in the small clinics mostly in the unrecognised Bedouin villages. Clinics in the unrecognised villages had a limited supply of electricity therefore all medication requiring refrigerators to be stored were unavailable. For example, Insulin ampules required refrigerators therefore diabetic patients needed to buy them from bigger health centres which meant travelling. .

‘Sometimes I would go to Beer-Sheva to buy my medication’ (Married woman, 38, interview 15)

The opening hours of Health Centre were during the day from 08:00-16:00 from Sunday to Thursday with a shorter day on Friday. There was no provision at most clinics during the late afternoon and early evening, and no cover at night or during the weekend in most clinics such as the Health Centre I was researching. In emergencies the ambulance services could only be called to recognised towns and villages or to the nearest main road. Many people dealt with the limited opening hours of the clinics by travelling to the Soroka hospital in Beer-Sheva which had paediatric and adult emergency rooms, or by attending clinics open later in the nearby Jewish cities of Dimona, Arad or Beer-Sheva or the few local clinics with evening opening hours.

'It is a big problem when I feel bad in the eveningthe clinic is closed in the afternoon and we can't go to clinic A (clinic in tribal area) in the evening. It is easier to go to one in Dimona (Jewish city)' (Married man, 53, interview 21)

'I live here next to the clinic. Sometimes in the night I feel bad and am in pain, I need to wait until the morning when the clinic opens. I will not wake up my son to take me to hospital. Last week my grandson fell and hurt himself so we took him to the hospital .A lhamdallah it was not a big wound' (Widow, 48, interview 17)

'I will not go to small clinic in the evening. It is better for us to go to the city (Dimona.) We will find the drugs certainly there instead to go and not get the drugs' (Married woman, 54, interview 12)

There were two small clinics that were open in the evening in rotation between 16:00-19:00 where patients registered at the Health Centre could visit in cases of emergencies. This was the only provision outside normal working hours which were 8:00 – 16:00, in general the peak hours of utilization the services were 08:00-11:00. The vast majority of client and patients who needed care would come in the morning. Owing to transport issues, they would often arrive long time before their scheduled appointments.

‘My appointment is at 10:30, I come with my son who teaches at a school near the clinic, I come at 7:30 when I am fasting for my glucose blood test, already I have a headache and feel dizzy’ (Married woman, 64, interview 14).

After patients receive their appointment time they sit and wait, some until 1pm. The health team explained and encouraged patients to make their appointments with doctors or nurses or for blood tests by telephone and to come at their appointment time. However they had not succeeded in this, owing to a number of reasons. Few houses had land line telephones in the town and certainly none in the unrecognised villages. While the Bedouin mostly used mobile phones, it was normally the men who owned them and they were mostly away during the day time working. Few women had their own phones for receiving or making calls. This meant that making appointments by phone was easier for men than women but few did it.

'There is no one to make an appointment for me by phone. I prefer to come here and see the doctor and take my medication; I will come in any case, so I will wait a little bit' (Interview, 3.A).

Therefore seeing patients by appointment, which in principle was meant to ensure less waiting time, less crowding and make care more available, was in reality, a barrier for most women. They continued coming early to the clinic and waiting their turn. The waiting time was an opportunity to meet and talk with women from other neighbourhoods or families but would often mean leaving children at home being cared for or waiting also for transport back to their homes if the clinic was not within walking distance.

In summary, health care provision was available but varied depending on the size of the clinic. Availability of specialist care was limited and not suited to the demographics and epidemiology of the Bedouin population by for example more, paediatric or specialist diabetes provision. As an Arab population with higher rates of diabetes and hypertension, cardiovascular conditions and obesity than the Jewish population, there could have been more routine monitoring of chronic conditions. However 70% of the Bedouin are under 25 and so young people form the majority of the population. There could have been more evening opening hours to make care available to men and also for women when men had returned from work. However, as most of the clinic staff did not live in the villages where the clinics were situated and arrived by cars or public transport, extended opening hours seemed difficult to provide and were not a priority. The next section reviews issues of accessibility.

Accessibility

According to UN special comment 14, the health services should be accessible and non-discriminatory and physical accessibility. The Bedouin towns and villages lack public transport. Some households live within reasonable walking distance of a clinic and many households own cars or pickup trucks. However, some women with ill children or elderly diabetic patients walk to the road which may be some distance away and wait for communal taxis, often Peugeot pickups to pass by. The distances vary from the main roads with scheduled bus services depending on where people live.

Although the health centre in which I conducted my field work was located in a recognised village, still 30% of the registered patients lived outside it. Inside the town there was no public transport and elderly people who lived far from the clinic relied on a family member to take them to the clinic when needed. The problem was more difficult for those who lived outside the town.

Many women who agreed to be interviewed when visiting the clinic, then refused to wait for the interview after their appointment with the doctor, as a car waiting for them. Some of them came back another time but others did not. Other patients from the same area often joined them on the journey going back home. There was public transport to the city of Beer-Sheva (where the hospital was located) and the towns of Dimona and Arad along the main roads but the journey to the main roads was often some distance and people relied on the pickups to get there.

Economic accessibility

Although Bedouin are covered by the governmental health insurance, they still need to pay a small amount of money for each prescribed treatment. There is also a 25% payment for each specialists or test when they are referred.

'Yes the doctor wrote me the prescription for the Insulin and changed the tablets to new tablets and it was expensive for me, so I didn't buy them. .'

(Married woman, 54, interview 8)

Diabetic patients usually have more than one health condition and they usually have between 3-7 types of medications so that the sum of them will be quite high for each patient. Most the women that I interviewed were under the age of 60, did not work and were not entitled to receive a pension yet, so for most of them their source of financial support was their husband or married and unmarried children.

'Oh my daughter, I have a full bag of medicines, just in the morning I take 12 tablets! I don't need diabetes to be ill- my medicines are enough.'

(Married woman, 54, interview 18).

'I have a pack of medicines -, they hurt my stomach and sometimes I take only half of them (Married woman, 49, interview 6)

Also there is the cost of transport.

'To come to the clinic I pay our neighbour to bring me here and he will come back to pick me up when I finish' (Married man, 65, interview 19)

'My nephew brought me and I paid for the car petrol, he will come back for me at 12 when he comes back from Beer-Sheva' (Woman, 62, interview 5)

The health ministry and the health providers' services did not have any culturally appropriate health program which provides health information regarding common health conditions amongst Bedouin community. Regarding diabetes, the majority of older patients with chronic conditions in this age group are illiterate in Arabic and Hebrew. Therefore any bulletins or flyers that might be found in the Bedouin clinics in Hebrew or Arabic languages are not appropriate and do not take into consideration the need of the Bedouin communities and therefore are not suitable for raising the awareness.

The health professionals acknowledged that the Bedouin patients lacked of knowledge and information regarding their health conditions. However they did not mention how it could be changed or what they had done to change it.

'They have no basis for understanding. There is a lack of information which is linked with a lack of awareness' (Clinic Nurse T).

'People's awareness has increased, but not enough. There is a lack of knowledge about diseases' (Clinic Bedouin doctor, Dr D).

From my non-participant observations during consultation sessions with a diabetic patient, there was limited information given to older female patients who did not speak Hebrew as the doctor struggled to communicate in limited Arabic using commands and short phrases.

‘The doctor opened her door and told the patient with a raised voice ‘Come in, sit down’ (odkhol, ugoodi)...Then she asked ‘What’s your problem? (shoo mushkelah’’ The older woman started to talk in Arab. The doctor stopped her with a hand gesture and said in Arabic Enough – where does it hurt?(bass,,, wain bowaja’?) The woman pointed to her knee, legs and shoulder. Then the doctor said “Yes it all hurts (kulloo boja’)” She then asked her to take off some of her clothes.” Take off your clothes – go to the couch (aglaa’y, rochi asarir)’” (fieldnotes from observation on 03.09.07)

Part of the lack of information accessibility was related to the some of the health professionals in the Health Centre and Hospital Out-patient Clinic being non Arabic speakers which affected all consultations and interactions between the staff and their Bedouin patients in particular explanations. This will be dealt with under the section on acceptability and clearly there was a difference in care between Arabic and non-Arabic speakers in terms of information.

It is important to mention that men are affected less than women by the lack of Arabic in consultations since they speak more Hebrew. This may link to why men seemed to be more informed about diabetes as will be shown in Chapter 5.

Acceptability of Health Care

According to UN General Comment 14 acceptability of health care provision includes sensitivity to the culture and lifestyle of patients, issues of gender and non-

discriminatory care to indigenous peoples and minorities. This is an area of the right to health which was problematic in the health care provision being offered to Negev Bedouin at the time of the research study.

The Bedouin form part of the Palestinian Arab minority within Israel and within that have a particular culture. The majority of the health professionals working with them are not Arab, not Bedouin and not fluent Arabic speakers and were often recent immigrants from the former Soviet Union. Working in rural clinics serving the Bedouin, was not a sought after position so that recent immigrants trained in medicine abroad, with relatively limited Hebrew were not unusual in the Bedouin clinics. More than 50% of the health professionals who were working in the clinics serving the Bedouin in the Negev did not speak Arabic creating a language barrier between the staff and the patients, especially women and children (NCF, 2010).

In the Health Centre where I conducted my study there were three health professionals who were Bedouin. There were four doctors of whom two were Bedouin. The Bedouin paediatrician was the Director of the Health Centre and the other paediatrician was a new immigrant from the former Soviet Union. One of the family doctors was Bedouin and the other from the former Soviet Union. There were three consultants coming one day per week and a nurse who accompanied the ophthalmologist and all were from the former Soviet Union. There were three nurses in the Health Centre –two were Jewish one had several years of experience of working with Bedouin, the second was a recent immigrant from the former Soviet Union and the third was Bedouin woman who had recently graduated from

university. In terms of the diabetic patient care, the two family doctors and the Bedouin nurse and the more experienced Jewish nurse.

In the Hospital Out-patient Diabetes clinic there were 3 consultants one Bedouin, and two were Jewish - one of whom was from the former Soviet Union. There were 2 nurses and a nutritionist, all Jewish, only one of them had experience working with the Bedouin.

The nurses who were not Arabic speakers had a few words of Arabic usually imperative verbs used as one word commands such as Come (tahal), Sit (ugood), Take (khuth), Go to the doctor (rooh ledoctor) . One was born in Israel with rudimentary Arabic from seven years working in the clinic who could use phrases such as 'Have you eaten anything? (alkalti hajar?) And would understand a one or two word answer such as 'bread' (khubz) or 'tea with sugar' (shay maa sukkar). The third nurse was Bedouin and was the only one in the Health Centre who had no linguistic communication problems. The lack of Arabic meant that health professionals often relied on younger family members such as sons to interpret for them.

Generally, in addition to the lack of Arabic, these doctors and nurses lacked knowledge of Bedouin culture, lifestyle and food consumption, and also had been given no professional cultural or linguistic training in dealing with Bedouin patients. This lack of training and language affected the accessibility and acceptability of care in terms of communication during the consultations if the patients were not Hebrew

speakers which were often the case with older women, and in terms of the health professionals' understandings of their Bedouin patients' lives and culture.

Clearly Bedouin health professionals had no linguistic problems and therefore there was more interaction in the consultations. The Bedouin doctor who treated diabetic patients was familiar with Bedouin food and the cultural behaviour. The patients talked more freely with him and discussed their food and treatment and more information was exchanged. He would mention the names of Bedouin dishes and he told them about the high amount of fat and sugar in their food such as when he talked to older diabetic woman:

'I know last night you ate half of tray of Makluba (a dish of rice and vegetables and chicken)'

To another man he remarked on the increase in seasonal home grown produce as a reason for high sugar levels:

'Your breakfast, lunch and dinner are just grapes and figs from your garden (bustaan) just now '

His appointment times were shorter than those of the other family doctor and patients called him 'the fast doctor'. He had worked in this Health Centre for a few years, which meant he knew the patients and their family members. Sometimes when the health team needed to contact patients but did not have a contact number they came to him and he would find some relative of the patients and asked him to tell him to come to the Health Centre.

The Bedouin nurse seemed to be busy all the time, with patients from different doctors coming to see her. She complained that patients from all units preferred to come to see her when the doctor asked them to go to a nurse for a check of their temperature, blood pressure, ECG, put of oxygen or inhalations, injections, dressings etc. She added that the head nurse was busy at managerial duties and many times she was out of the clinic at meetings. Both she and the patients said that they didn't want to go the other nurse as she was new and slow.

The Bedouin nurse had the highest qualification through her nursing degree from the three of them, and was the most recently qualified. She complained about the constant pressure of work, that she went home so tired and this affected her family life. She was clearly doing more than the other two nurses owing to the preferences of the patients.

The health professionals, both Jewish and Bedouin had many stereotypes thought that patients in general were careless about their health, especially those with diabetes. The diabetic nurse specialist in outpatient clinic said:

'If I told you, Bedouin women come and sit with me, if they are worried, sad or frightened? NO it does not happen...for them to take the responsibility to do what we require them to do...this is one of the main barriers' (Diabetic nurse, Y).

The nutritionist who worked in the outpatient specialist clinic said

'They don't take responsibility for their lives. Many of them don't come to their appointments'.

Some health professionals insisted in their interviews that the problem of poor diabetes management lay within the Bedouin community. They mentioned more than once that they were giving their highest care but the Bedouin were not adhering to their advice.

'As I said the problem is not with the doctor. The doctor gives comprehensive explanations. The patient knows what he should eat and what he shouldn't, what he is allowed and what he is not' (Clinic Bedouin doctor, Dr D).

'Diabetes control in the Bedouin is like stocks and shares, some patients' diabetes is well controlled some not...some will never be controlled' (Clinic doctor, Dr C).

The diabetic specialist blamed the rapid changes of Bedouin lifestyle during the past decades which caused a huge change in their levels of physical activity and diet and left them exposed to being overweight and to obesity.

'It's because their lifestyle changed completely. We take people who survived well for a long time in the desert under difficult living conditions. And we took these people and put them in the 21th century lifestyle with MacDonald's, Falafel, lots of supermarkets, Coke, and sweets and all this kind of stuff. They become overweight and their system still stores energy, and this is what happens. Their life has changed completely.' (Specialist doctor, Dr A).

Others mentioned a lack of awareness and understanding about diabetes as the main difficulties Bedouin patients faced was their trouble in maintaining their blood levels within normal ranges. They reported that Bedouin patients did not understand what they were telling them about diabetes, especially older people (which are the main age group that have diabetes).

'In my opinion there is an increase in the prevalence of diabetes amongst Bedouin. In the past, people had no awareness of chronic diseases. Today they get diabetes, hypertension, and cardiovascular diseases. People's awareness has increased, but not enough. There is a lack of knowledge about diseases' (Clinic Bedouin doctor, Dr D).

Some health professionals thought that Bedouin patients in general were careless about their health, especially those with diabetes. Bedouin patients did not come in time for their appointments. Some patients would ask for sugar blood tests when they came to the health centre for any reason such as accompanying family members, coming to the pharmacy or having an appointment with the GP or specialist for other conditions.

'Bedouin do not take responsibility for their disease, and do not do what we require them to do' (Specialist nurse X).

One of the health professionals did not think the Bedouin were careless, but that the problem was a lack of awareness and knowledge about the disease. He thought that because of the low education level, they might need more meetings and more explanation sessions.

'They are not careless, but the problem is that the awareness is so limited. In the Jewish sector the patients might need one or two meetings and they will understand exactly what is going in... Maybe the Bedouin need ten meetings. I am telling you the Bedouin ignore the disease. It does not matter which disease, even if it is cancer, they see it as bad thing, and they will be ashamed of it. If any of them get a disease they will ask me not to tell anyone. The disease becomes a secret and after he dies, they will say the death is from Allah' (Clinic Bedouin doctor, Dr D).

The nutritionist who worked in the outpatient diabetes clinic was the only nutritionist dealing with Bedouin patients. She said:

"They don't take responsibility for their lives. Many of them don't come to their appointments" (Nutritionist).

Lack of knowledge and culture barriers were mentioned by the health professionals as obstacles for the Bedouin patients to obtain health services and understand their conditions. However, they did not mention that lack training about Bedouin culture and lifestyle was their responsibility. They repeated the views that the culture of the Bedouin was stopping them from obtaining good health results and adhering to their recommendations. They stressed that they were providing comprehensive health care to the Bedouin.

Language was not raised as a barrier to care by non-Arabic speaking health professionals in the Health Centre, despite them asking me to translate for them when I was observing their consultations. However, the health team in the Hospital

Outpatient Clinic recognised that the lack of Arabic was a barrier for explaining and giving better care. One nurse in the Outpatient clinic talked about language and knowledge of Bedouin culture as a barrier which prevented her from communicating effectively and explaining the disease.

'For me language is a big barrier. In addition, I don't know the Bedouin culture and customs. I think they are also struggling with the language, and I am not from their culture...and this does not make things easy for them. I need to know many things about the Bedouin about their food, customs, and their traditions. I think it strange to come and tell people to eat this and not to eat that without knowing their culture. (Specialist nurse Y)

However, I had been asked to translate for the health professionals when I was in the room to observe the sessions.

Conclusions

This chapter discusses the four elements AAAQ of the right to health approach. In terms of quality of care medical records were incomplete, and the nursing follow up records revealed missing data in the patients' files. It is also exposed the lack of diabetes guidelines for the Bedouin. Diabetes records were reviewed in term of variables which were relevant to the follow up of the diabetic patients such as numbers of follow up, level of HbA1c, treatment types, level of diabetes control

The prevalence of diabetes in the Health Centre and how it was measured and compared with other studies of the Bedouin community was analysed and discussed.

The results showed that previous studies reported an under estimation of the prevalence of diabetes.

Non participant observation of the daily routine work of nurses and the quality of diabetic patients' reviews uncovered of many areas of care which could be improved.

In terms of availability there were problems of the opening time of the clinics, availability of all the medications. Accessibility was affected the low socioeconomic status of the Bedouin community such as lack of transport. Acceptability was undermined by lack of understanding of the health professionals to the Bedouin culture and language barriers for non Arabic speakers.

Overall, there were many of areas that need to be tackled to improve the AAAQ amongst Negev Bedouin. These findings showed that these diabetic Negev Bedouin, part of the marginalized Arab minority were receiving a poor quality of health care provision that did not meet the rights to health care as stipulated in the UN Special Comment 14.

Chapter 5

Explanatory Models and explanations of health inequalities

This chapter will address the research question to what extent the materialist and socio-behavioural explanations of health inequalities extend understandings of the experiences and management of diabetes care and of marginalised Bedouin in the Negev?

There are different explanations of health inequalities as discussed in the Literature Review in Chapter 1 (p43-46). The most relevant explanations of the social determinants of health inequalities for the situation of Negev Bedouin with diabetes are the neo-materialist, materialist and the socio-behavioural explanations and these will be focused on in this chapter to address the research question using data from interviews with patients and health professionals. In addition, the explanatory models of illness that Kleinman (2006) identified as being utilised by both professionals and patients are analysed to identify the differences and similarities between them.

Neo-materialist and Materialist explanation and explanatory models

Neo materialist and Materialist approaches are defined by a “combination of negative exposures and lack of resources held by individuals, along with systematic under-investment across a wide range of human, cultural and political-economic processes” (Lynch 2000 p1001). The systematic lack of investment in social welfare combined with negative material circumstances and lack of resources to manage such impacts result into health inequalities.

There are many measurable elements linked with negative health outcomes including, the gaps between the rich and poor, types of employment and levels of unemployment, quality of housing, the quality of the physical environment. The neo-materialist explanation focuses on government policies and how these affect the overall distribution of resources whilst the materialist approach focuses on the household and individual level of resources within the context of the political and economic social structure.

As it explained in chapter 2 (p45) the materialist explanation views health inequalities as being due to differences in material circumstances such as the working environment and housing conditions. An example of the materialist explanation applied to the Negev Bedouin is the high level of stunting in growth among young children, which was linked to living in poor housing conditions without running water (Forman 1995) with high rates of gastro-enteritis and asthma linked to their living conditions (Bilenko, Fraser et al. 1999).

From the neo-materialist and materialist standpoint there are many factors associated with poor health amongst the Bedouin that can be attributed to the

political and social structure of Israeli society. The Bedouin have the highest rate of unemployment in Israel, the lowest level of education (see Chapter 2 p 46), and the majority of them live in unrecognised villages which lack infrastructure, appropriate housing, roads, water and electricity.

The health care professionals were aware of how socially disadvantaged the Bedouin were. The difficult socio-economic situation of Bedouin was raised by health professionals as part of their explanatory model (Kleinman et al 2006) for the lack of adherence to treatment for diabetes both in terms of medication and attending the clinic.

'... also the socio-economic situation is a serious problem; there is a lack of money to buy medication. Also another problem is of transport and access' (Clinic Nurse T).

'Their socioeconomic situation is a factor and they don't arrive sometimes because of that' (Specialist nurse Y).

Some felt that the patients living in unrecognised villages or encampments which they referred to as tribal areas, were more affected and that in particular women had less resources within their households to buy medicines. This gender difference was particularly significant as the rate of diabetes was higher amongst women than men (table 4.3, chapter 4 page 120).

'The economic situation affects more people in the tribal areas. I don't come across a single woman from the recognised village who does not take her medication because she does not have money, but from the tribal area yes I have. In general

people buy their medication. In the tribal area their economic situation is difficult. We see they don't take their medications.... we try to direct them about the importance of medication which they should take.

'I have the impression that women tend not to take medication more, or take half of it. We diagnose more women in the tribal area, men tend to come less to the clinic (Clinic nurse W).

Bedouin interviewees also attributed the high rate of diabetes to the socioeconomic conditions.

'I think the economic situation is responsible for diabetes in Bedouin community' (Married man, 55, interview 24)

'Bedouin live in poverty and can't afford to buy fruit and vegetables every week' (Group 3, married woman, 20s).

Women talked the cost of medicines and how sometimes they did not buy them owing to other priorities. Women with children received monthly Children's Allowances paid directly to them and so all had some income which was generally but not always supplemented by their husbands as practices varied.

'My mother spends 500 shekels every month for her medicines -, it's so expensive' (Group 7, unmarried woman, 20s).

'You want me to tell you the truth? I don't buy all my medicines. I don't have money to buy them and my daughters ask me to buy things for them' (Group 6, married woman, 50s).

The rise in diabetes worldwide is part of the increase in non-communicable cardiovascular diseases amongst this population and for the Bedouin population is connected to the transition from being semi-nomadic to being sedentary. As explained in Chapter 2, the Israeli government had a policy of displacing Bedouin tribes from their agricultural and grazing areas, and settling them in planned villages. Only a very small minority continue a semi-nomadic lifestyle and almost all are living in planned or unrecognised villages.

Most women do not work outside the home, and have few opportunities for physical exercise aside from child care. They no longer herd flocks or work in the fields. Men undertake paid wage labour, and often do the shopping in the cities and towns and women often send children to the shops locally. The change in lifestyle has been encouraged as part of government policy and the way in which women's lives have changed has been shaped by this but also by Bedouin social and cultural traditions of women's roles – a combination of the neo-materialist, the materialist and the socio-behavioural.

Health professionals' and Bedouin often raised the changes of Bedouin lifestyle during the past decades as a factor in the huge change in their levels of physical activity and diet.

This is an issue which showed how the lay and professional explanatory models of illness overlapped.

'The problem is that Bedouin patients eat the wrong diet, they eat everything never think about their diabetes and how it can be affecting them'. (Clinic Bedouin doctor, Dr D).

'Women don't find special food for diabetes to eat usually as they eat with the rest of the family. It's difficult for them.' (Clinic nurse, T)

'The change in Bedouin life is responsible for all these new diseases. Bedouin were healthy people in past, they could walk long distances without be tired. Today Bedouin are fat people.' (Group 7, unmarried woman 4, 20s).

Some interviewees mentioned the distance from the clinic and lack of public transport as barrier to receive health care when they required it. Sometimes being overweight or obese with knee or feet problems (part of the risk factors and complications of diabetes) exacerbated these problems of access.

'I need to walk a long way to get to the clinic, as there is no transport. Sometimes I'm not able to walk and come to the clinic for my diabetes review' (Married woman, 61, interview 29).

'I can't walk long distances. I am tortured when I walk to the clinic. I need sit down in the street twice or three times to rest and I have knee pain.' (Married woman, 62, interview 5)

'Once they (health staff) found sugar high in my body and they asked me to go to the hospital urgently. I walked to main road I felt 'my spirit left' (roohi

talaat minee). I waited there at the bus stop a long time for the bus and went to hospital'. (Married woman, 55, interview 7)

People that did not live in the village complained about the lack of electricity in their homes and how this affected their diet.

'I eat vegetables and fruit only on the same day that we buy it or the next day. It gets spoiled so fast in the hot weather and we don't have refrigerator. There is no electricity here' (Married woman, 40, interview 10)

Socio-behavioural explanations of inequalities –

Explanatory Models of illness

The socio-behavioural explanation views health inequalities as a result of people's behaviour and choices. It is argued that people are responsible for their diet, lack of exercise and smoking. This type of explanation of health inequalities is relevant to considering and analysing how both Bedouin and health professionals have explanatory models of diabetes that utilise socio-behavioural issues.

Amongst the Negev Bedouin, many health professionals consider that Bedouin have high rates of diabetes owing to a diet heavy in sugar and lipid fats and a lack of exercise. However, the socio-cultural environment prevents women exercising and other factors such as the lack of transport to outlets of fresh fruit, along with a lack of availability of fresh food in nearby stores, thus an explanation that focuses on

individuals does not take these social factors into account (Abu-Saad et al 2009, Weitzman et al. 2001).

The diabetic specialist expressed the view that the rapid changes of Bedouin lifestyle during the past decades had caused a huge change in their levels of physical activity and diet and left them exposed to being overweight and to obesity.

'It's because their lifestyle changed completely. We take people who survived well for a long time in the desert under difficult living conditions. And we took these people and put them in the 21th century lifestyle with MacDonald's, Falafel, lots of supermarkets, Coke, and sweets and all this kind of stuff. They become overweight and their system still stores energy, and this is what happens. Their life has changed completely.' (Specialist doctor, Dr A).

Bedouin refer to diabetes as (*indee sukary*). In Arabic the name for diabetes is (*sukary*), which derives from the Arabic word for sugar (*sukar*). Therefore everyone understands that it is a condition to do with sugar.

'...the result showed that I have diabetes (sukary)' (Married Woman, 54, interview 8).

In general, Bedouin are more likely to associate the condition with white sugar, hence they think that a person who has diabetes should not drink tea or coffee with sugar. Sometimes they make a link between drinks or food that taste sweet and diabetes. Food or drink that tastes bitter whilst containing high amounts of sugar are not considered a risk. For example, grapefruit juice is a common drink offered to

people with diabetes and is often brought to hospitalized patients despite the fact that the amount of sugar in grapefruit juice is higher than other soft drinks such as Coca-Cola and Pepsi which they are prohibited from bringing to patients.

Lay explanatory models of Bedouin

Below are three accounts from interviewees about how they began to feel ill, and experienced signs of physical signs of sickness. The first account links the onset of signs of sickness to being very thirsty, urinating frequently and having problems with her vision. Whereas the second account focuses on visual problems and the third account focused on being thirsty.

‘I was preparing for my daughter’s wedding. I was so busy going out every day to shopping centres. It was summer and the weather was so hot. I felt hot and dizzy. The first day I drank three bottles of soft drinks each of two litres. I could not drink water because it tasted bitter. I was drinking soft drinks and after ten minutes going to the bathroom and emptying all that I drank. I did not know at the time I had diabetes. People were looking at my face and saying “What has happened to you? Why are your eyes shining?” I started to have blurred vision and lost my sight. I went to the clinic and told the doctor about my urine and blurred vision. They weighed me and found I had lost six kilos. The doctor told me you should go immediately to the emergency room at the hospital. She said:

'They (health professionals) told me don't go by public transport, take a taxi. I could not walk properly, my feet were stiff. I started to walk from side to side like a car when the driver has lost control of the steering wheel' (Married woman, 55, interview 7).

'It started when I began to get a feeling of mist in my eyes when I was sweeping the floor. I felt as if a cloud was covering my eyes. I went to the clinic; they did a blood test and said that everything was normal. The cloud in my eyes continued to annoy me, so I went to a private doctor. He checked me and told me I had diabetes. I brought the letter to my doctor in the clinic and they started to do tests and gave me medication' (Married woman, 54, interview 8).

'My mouth was dry all the time, even at night I started to wake up thirsty and drink water. Now I understand that when my mouth is dry my sugar is high' (Widow, 48, interview 17).

Some women tended to connect the onset of diabetes with traumatic events which happened to their close or extended family such as the death of a family member, a husband marrying a second wife, or problems occurring in their children's lives. They reported they had health problems after they had experienced being unhappy so that being sad was associated with the onset of diabetes.

'Diabetes started with me after my son's death, I am sure about that. This happened four years ago and since then I have had diabetes' (Divorced woman, 56, interview 9).

'I had diabetes after my mother passed away. I was devastated and felt so bad... and then I got diabetes from that' (Widow, 52, interview 11).

In some accounts, women elided feeling unhappy and being physically unwell. This is part of expressing unhappiness or anger somatically which is often the case with people who are less empowered such as children, or women in Arab societies (Al-Krenawi and Graham, 1996, Al-Krenawi et al, 2002). Sometimes they were taken to the clinic owing to being distressed and the staff at the clinic would use the visit to screen for hypertension and diabetes. This first account makes an association with her son's death but also that gaining weight resulted in diabetes (Arcury et al 2005).

'You know every heart carries its burden and my son's death affected me. I used to drink a lot of tea. The doctor has had to warn me about food. He told me 'you do not have diabetes. If you gain weight you will have it, and this happened. My weight increased and when I did the blood test, they found diabetes' (Married woman, 64, interview 14).

The next two accounts are examples of being very distressed and being screened when they went to the clinic.

'One of my relatives died. When I heard the news I started to scream, yell and cry... then I felt so bad that my son took me to the clinic and when they checked me they told me I had diabetes' (Widow, 63, interview 28).

'My daughter had problems with her husband since she married and after a few months she got divorced. I was under pressure and women gossiped about me and my daughter. I felt bad and... I had a headache all the time...When I went to a doctor he examined me and told me that I have diabetes... all the problems came together...' (Married woman, 54, interview 18).

A number of women reported they felt ill and then got the diabetes after their husband married a second wife.

'When my husband married another woman without telling me, I became depressed and after a few months I got diabetes... I was so sad and angry but I could not do anything' (Married woman, 54, interview 12).

'My husband, who's now my ex, married and this affected me badly. This made me depressed and ill, and then the death of my son came and broke me' (Divorced woman, 56, interview 9).

'It started after I was miserable....he married I remember that and when I went to the clinic they told me I had diabetes' (Married woman, 55, interview 4).

Here is an account, which starts with a broken leg and then continues with the signs of thirst and excessive urination leading to a clinic visit and diagnosis.

'I broke my leg a year ago. I lay in bed for 45 days... I was crying all the time and asking God why this had happened to me... I was healthy although I

was 61, I was not used to someone bringing me food in bed... I was gloomy every day. After they removed the gypsum I felt dizzy and had mist in my eyes. I started to urinate a lot and drink large amounts of water. Before that I did not use to drink much... I went to the doctor. He took a drop of blood from my finger and told me the sugar is 400 in my blood. He gave me tablets and asked me to come back after three months. (Widow, 59, interview 13).

Some women reported diabetes starting when they were pregnant and continuing subsequently so that pregnancy was the trigger for the condition.

'I was pregnant and got diabetes... after I had my baby I went for a blood test and then they told me that the diabetes had not gone away' (Married woman, 49, interview 6).

'Now I am fine, praise be to Allah, all my diabetes and pressure examinations are good. Diabetes started with my pregnancy and continued with me' (Married woman, 40, interview 10).

A few patients reported that they found out about the diabetes by accident after they did blood tests for another health condition or with a general blood test.

'In the beginning I did not have diabetes I had only pressure (hypertension)...but I felt so bad for a while that my children told me to go and check... I went to the clinic and they tested my blood and urine and found diabetes' (Widow, 58, interview 3).

'I felt well but I went to a general check-up, and they found that I had diabetes... I'm still fine'. (Married man, 55, interview 20)

One man mentioned that when he felt changes in his general health, he believed this happened as a result of black magic (*seher*) that had been cast by his brother. Whilst another woman felt this illness had arrived from Allah.

'In the beginning I didn't know what was happening with me... I felt something going on with me...I suspected that my brother had done black magic to me... I felt blood moving in my head and legs. I went to the doctor and when they checked my blood they found diabetes... I thought about black magic' (Married man, 52, interview 1).

'...this is from Allah, and anything from him is good, we can't say no' (Married woman, 54, interview 18)

These accounts from interviewees of how their diabetes started show that the physical signs were often recognised as unusual. A traumatic event was often perceived as triggering the illness or weight gain and pregnancy. There were also explanations of the reason for the illness that involved the supernatural.

Health professionals would confirm the physical changes as being part of the onset of diabetes and also that weight gain or previous gestational diabetes in pregnancy could be a risk factor. The explanations drawing on traumatic events, or supernatural powers however, were not part of their explanatory models which focused on socio-economic conditions and diet and lifestyle.

Socio-Behavioural context of dietary habits

Food plays an important part in Bedouin social life. Bedouin occasions and hospitality requires food and drink as a sign of generosity. They drink strong coffee without sugar, and the tea with plenty of it. The tea should taste sweet. Hot drinks are served regularly with sweets such *baklava*, *Namura*, biscuits and waffles.

In the household natural group interviews I conducted, I was greeted with sweet tea made in a kettle and served in small glasses carried round on a tray. Typically, everyone present drank the same tea. Biscuits, waffles, and sometimes fruit, were also served. Typical fruit were grapes and watermelons. Diabetic women who were at these gatherings drank the same tea and ate like everyone else. To accept tea and snacks was considered polite behaviour.

The social and cultural significance of hospitality posed problems for people trying to control their diet. The participants reported different behaviours around food, outside the household, within the household and when they ate alone. Few of the interviewees managed to avoid sweets in company. Others found it only possible when by themselves.

There was a clear gender difference in terms of how able women and men felt about modifying their diet when guests or within the family. Men reported controlling their diet in company. They reported that it was important that people, especially friends should know about their diabetes, secondly they said they did not have a problem with telling people, and thirdly they said they felt able to ask for what they want to drink. They felt empowered to keep requesting tea without sugar when visiting

others. Some of the men mentioned that they drank tea or coffee without sugar, and they would ask for water or Bedouin coffee which is served without sugar. They were willing to tell their friends or others who served them that they had diabetes and they were not allowed to have drinks with sugar.

'I will ask for water when they serve me tea with sugar. All my friends know I have diabetes and they will understand' (Married man, 55, interview 20).

'I don't have a problem telling people that I have diabetes and I ask them to make me tea with less sugar. Mostly I drink Bedouin coffee'.

'When I am at home, I drink my tea and coffee with sweetener' (Married man, 52, interview 1).

'I don't drink tea at all, and drink coffee without sugar, but when people serve me I will just drink a little bit' (Married man, 65, interview 19).

It would seem that the higher status of men in this patriarchal society allowed them to modify their consumption by requesting that women made the tea without sugar or the men make coffee in the guest tent without sugar for them.

This contrasted with the women who felt they had to fit in. Several women talked of 'sipping their drinks' in order not to embarrass the host by refusing drinks at family gatherings or events. Others mentioned they did not attend the events as they were shy of refusing to eat and drink as it would offend the host.

'My relatives had a wedding few weeks ago. I didn't go because I was scared to eat meat and fat, as I can't refuse it. But when the women are gathered, I

drink juice or eat sweets, I feel shy saying no'. (Married woman, 49, interview 6)

The interviewees understood that their condition had connections with food containing sugar. They had different understandings regarding the association of diabetes to liquid drinks and food. Usually they connected diabetes with drinks such as tea and coffee. They also said that they eat non fatty food. They usually mentioned that they had stopped or cut down on the amount of sugar in tea or coffee. They cut down the amount of sugar by drinking fewer cups of tea though, rather than by making the tea with less sugar.

'I just drink a few sips of tea as I know that I can't drink it' (Widow, 58, interview 3).

'I am drinking tea with sugar, this is the truth especially when relatives are coming or I am going to my neighbours, but sometimes when it tastes too sugary I will only have one or two sips' (Married woman, 55, interview 4).

'I don't like to embarrass people when they serve tea. I will take a few sips and eat a little bit from the sweets' (Married woman, 54, interview 18).

Some of the interviewees, mostly women, accepted tea with sugar when they were served it at events or at gatherings of women even when they knew it would affect their diabetes but they were careful to drink it without sugar when alone. This happened because it was not considered acceptable to refuse food or drink served by a host. Some of the diabetic patients felt embarrassed refusing drinks, believing it would humiliate their host. They preferred to flatter the host with drinking a few sips

of tea or accepting soft drinks. Another reason might be that people want to keep their health condition hidden, and so they would drink and eat as normal in social gatherings.

The majority of the women interviewed and all the men in this study did not prepare their own tea so they could not control the amount of sugar in the tea especially when it was prepared for the whole family.

'My daughter adds sugar to my tea, not a lot just to make it taste good, and usually I drink one cup of coffee with sugar when my husband comes back from work' (Married woman, 49, interview 6).

Few managed to avoid sweets and drinks with sugar in company. Others found it possible to control their diet only when they were alone.

'I drink my tea and herbs bitter... without sugar at all' (Married woman, 54, interview 16).

'I drink tea once or twice a day without sugar; I drink fenugreek every day without sugar' (Married woman, 54, interview 18).

'I don't eat or drink with my family, I wake up early and cook barley with olive oil and will drink my tea with a little bit of sugar' (Widow, 52, interview 11).

A few women reported that they refused to eat sweets and drink soft drinks or sweet tea at family events and women's gatherings.

'When I am invited to family events or when women gather I usually refuse to drink soft drinks or tea with sugar. I will say I have diabetes. I will eat from the served food but I refuse sweets' (Married women, 54, interview 8).

Many interviewees mentioned the word *akhabas* (*enkhabas* plural) or *takhbes* (noun form). This is a colloquial way of saying among Bedouin that they do not pay attention to what they are eating, and they mix many types of food together. They used this word to show that they eat food that they are not supposed to eat, despite knowing it should be avoided.

Social eating posed a problem for many in managing what they ate and drank. Some of the study participants tried to eat less fat by eating less food or by eating meat without fat or rice. The interviewees suggested that they thought that the Bedouin way of eating and drinking when visiting or socialising and aspects of the Bedouin diet was, in the words of one woman, 'our problem'.

'We eat everything. We should watch our food and try to eat more salads and less meat and rice, but at social events we can't control ourselves' (Married man, 52, interview 1).

'When they serve me sweets I try to eat a little bit, but I can't not eat a lot' (Widow, 58, interview 3).

'I pay attention to food, I don't eat a lot, sometimes I only eat half a pita bread without anything, and at other times the whole of the pita bread. But the sugar is still high, if we cook chicken I will take off all the skin' (Married woman, 49, interview 6).

'I eat what we have at home. When I attend a wedding I will eat little bit from the meat with bread not rice. Our problem is that we don't care about what we eat' (Married woman, 55, interview 4).

'We don't pay attention to our food; we shouldn't eat so much food' (Married woman, 55, interview 4).

'I pay attention to my food unlike others who are careless (Ana ma akhabas), I really eat only bread with tomatoes, I don't eat fruit often, maybe once a week' (Married woman, 49, interview 6).

With these difficulties in managing their intake of food and drink, some interviewees reported fasting. They said that they fasted or limited their food intake to keep their sugar levels low. They did it especially on days before they were due to come to the clinic for check-ups. They mentioned eating a little bit of food only to be able to take the medication. However they stressed this did not show low sugar levels every time.

'Yesterday, I ate at 10 am, when my daughter cooked and I just tasted the food to take my tablets. I had no lunch and dinner and today I came and the sugar is still 160, high. What am I supposed to do? (Widow, 58, interview 3)

'I eat just one meal a day. I don't feel I'm hungry and my sugar is normal' (Married woman, 40, interview 10)

A few interviewees felt pessimistic regarding managing their diabetes and they said whatever they did the sugar in their body would be high. It might be because of that reason that they gave up on keeping to diets which were low in sugar and fat.

'Am I not allowed to eat lunch today as well?!... How can I live?' (Widow, 58, interview 3)

'Even if I eat a special diet, the sugar will be high all the time' (Married woman, 54, interview 12).

Some patients said that they would eat what they have at home or what the family usually ate and would not follow the recommendations of the health professionals. The reasons they gave being that they could not eat 'a special diet', or that they did not like vegetables, and that they would eat what is cooked at home.

'I can't eat what they (health professionals) are asking me to eat, the special diet, I will eat our food... I will eat what we cook at home' (Married woman, 55, interview 7)

'I eat normal food with my family, but they told me to cut down on the fat in the food and sugar in the tea and I am trying to do that' (Widow, 59, interview 13).

Others had information about the benefits of vegetables and fruit for managing their diabetes but they did not eat them for different reasons.

'They (health professionals) told us about food, and once there was a meeting for diabetic patients at the clinic. Each patient got a booklet about

food. My daughter read it and it recommended eating fruit and vegetables such as lettuce and parsley. I don't like to eat vegetables ... the booklet says not to drink tea with sugar and I do. I don't follow it' (Married women, 64, interview 14).

'I don't eat fruit, even when my sons brought me pears and apples. I don't eat them' (Married woman, 49, interview 6).

Bedouin women with diabetes are mostly over 40 years old. Traditional Bedouin diet was mainly composed of bread made daily in the home and pulses such as lentils cooked in tomato puree with meat on special occasions. So in childhood they had a limited consumption of fruit and vegetables which were seasonal and limited. Therefore although fruit and vegetables are available and plentiful in the markets, their purchase relies on money and access.

A few women made huge efforts to manage their diabetes through their diet.

'I pay attention to my food, I will not eat any kind of sweets at all, and I drink the tea like the Jews without sugar. I have stopped eating stuffed food; I eat just red meat without any fat. I eat a small portion of wholemeal pita bread and I never eat until my stomach is full, I should take care of my health' (Widow, 58, interview 3)

Bread was mentioned many times as one of the main staple foods; Bedouin eat it with each meal. Some will eat just bread during the day in order to take their tablets.

'I eat normally with my family, I eat the bread which I make at home, and maybe this is the problem. I can't afford to buy the bread that they (health professionals) ask' (Married woman, 54, interview 18).

'The bread and the sweets are a big problem for diabetics' (Married man, 65, interview 19).

'I eat mostly soup with bread. Maybe in the weekend when my family gathers, we cook chicken and I eat with them... I eat bits during the day because I need to take tablets... They (health professionals) said for diabetes you need a lot of foods... I don't eat' (Married women, 54, interview 16)

Men showed that they had more information regarding the kind of foods which are suitable for diabetics as they mentioned eating vegetables, fruit, grilled meat and chicken more often. In addition some of them gave recommendations to others about what they should do to keep their diabetes under control.

'I eat salads and grilled meat or chicken' (Married man, 55, interview 20)

'I try to eat healthy food and follow what the nurse in the clinic advises me, I don't drink any soft drink or tea with sugar at all' (Married man, 74, interview 26)

'I stopped eating food with fat; I reduced the fat in my diet. I like sweets and can't stop eating them but I will take 2 tablets instead of one when I eat sweets' (Married man, 56, interview 30)

'The important thing is to not eat what is going to harm you. You should not drink tea with sugar; we should eat salad and olive oil and vegetables and less fat and meat. I know some people can't control themselves and are careless (akhabas) about what they eat at events and they will say this will not affect them, but they will not sleep during the night and their sugar levels will go sky high' (Married man, 52, interview 1)

Through the natural focus groups I met younger Bedouin women. In general, they demonstrated more knowledge about wellbeing and illness compared to older women, even than those with diabetes. The young women were usually daughters or daughters in law who were present when I arrived after an advance announcement about the day and the time of the meeting. These women talked in more detail about their views regarding food and exercise. One lady demonstrated knowledge about what she can and cannot do. She changed her diet after she developed diabetes and started to cook healthier food for her family.

'I don't eat sweets at all, and never Arabic sweets... I don't eat fat and sour cream nor cheese or milk...I started to cook with olive oil and my family liked it. Also I started to use wholemeal wheat and they started to like that as well' (Group 3, 1, 60s, diabetic)

Another woman mentioned that she cut down on the amount of food she ate.

'I eat less than before... I started to cut down on the amount of sugar in my tea. Some people don't like this kind of tea...I pay attention to food (ma akhabas)' (Group 3, 2, 60s diabetic).

Another woman tried to change her diet but this did not help control her diabetes.

'I'm doing a hard diet... I started not eating bread, and stopped eating sweets... it's so difficult but this is not helping' (Group 3, 3, 40s diabetic)

Another told the group how she dealt with diabetes by not doing anything and she shocked them.

'I eat fruit just once or twice a month...I eat anything, I don't care about the amount of food I eat until I am full. Anything they put out for dinner I eat' (Group 3, 4, 50s, diabetic).

It is clear that all interviewees knew what health professionals had advised them to do in relation to diet. They reported that they had to avoid sweet drinks but not every interviewee modified their diet in line with these recommendations. Unlike the health professionals, tea and coffee were made differently in kettles or coffee pots that served everyone and food was eaten from communal bowls rather than individual plates. This meant that there was less control over individual preparation and consumption. Also most of the cooking was done by younger members of the family.

There were clear gender differences in the ability to modify diet. Women, on the whole, reported that conforming to social rules of hospitality when visiting was necessary and that even at home, being different was unfeasible. Men, on the other hand, seemed to feel able to request adjustments when visiting and at home. This

would seem to reflect the different social status of men and women in Bedouin society.

It is not clear if the content of the dietary advice was adapted to the Bedouin lifestyle. For example eating more lean meat is expensive and the main diet of Bedouin is light in meat. It is harder to alter food consumption when living in a large household. Older women on the whole did not cook – their daughters in law and daughters did the cooking. However there were some participants that modified their food intake and diet and others who did not. It is clear that diet is embedded in a socio-cultural context with particular gendered behaviours which the advice given by health professionals was not adapted to. . Rather they were blamed for their ‘wrong’ diet. One doctor believed that although Bedouin patients took their drugs, they continued eating as they did before the diagnosis.

‘Today in my opinion people come and take their medication. The problem is that diabetic patients eat the wrong diet’. (Clinic Bedouin doctor, Dr D).

Similarly advice from health professionals concerning physical activity was not cognisant of the socio-cultural and behavioural context of Bedouin life.

Physical activity and diabetes

One of the recommendations that Bedouin diabetic patients heard from the health professionals was to increase their physical activity. Patients were advised to do more exercise and sport although Doctor.

'You can't find Bedouin do exercise or walk to lose weight or to be healthy, it's not in their culture'(Clinic Bedouin doctor, Dr D).

'It's cultural norms, women can't walk for the aim of walk, they walk for purpose to come to clinic to go market. It is still not in our culture to understand that person might walk to improve his health.'

(Specialist doctor, Dr B)

Whereas when semi-nomadic, all the family would be involved in herding and agriculture as part of daily life, sport or exercise is not common amongst settled Bedouin. There were no facilities such as gyms in the villages. It is acceptable for boys and young men to play football and walk or run but older men do not participate in organised sport although they can walk freely. Women can only generally walk in groups and do so to go to the clinic or market. The idea of physical activity as part of leisure was not familiar or accepted. The only type of sport participants mentioned doing was walking, however the majority, especially women talked about walking or activity with purpose. As with diet, there were clear gender differences between women and men in relation to physical activity.

Three forms of physical activities were mentioned by the interviewees: that associated with work or activities outside the home by men mainly, and indoor activities or housework by women with walking mentioned by both men and women.

Bedouin women conflated the notion of physical activity with housework. Amongst all those who answered positively to 'taking part in exercise', usually meant housework. They usually stressed that it was very hard work and it made them tired.

This woman said:

'My mother does all the housework by herself...if my husband is not at home I will come to help her' (Group 3, 5, 20s)

Another woman who lived by herself said that for her, exercise was doing housework and cooking.

'I do the housework by myself, and cook only what the doctor tells me to eat for my diabetes' (Group 3, 4, 50s, diabetic)

Bedouin men tended to walk more. They visited the city, walked to the mosque or to the men's guest section which was often in a tent nearby, or in a local leader's home. (*shiq*).

Many interviewees, especially women, reported that they were prevented from walking or doing housework by problems with their knees or feet.

'I can't walk, I have a problem with my knees and they hurt' (Married woman, 49, interview 6).

'Ever since my leg was broken, I haven't been able to walk for long distances' (Widow, 59, interview 13)

It is expected in Bedouin culture that as women age, their daughters and daughters – in-law will do the housework. Generally most of women I interviewed, understood physical activity as housework. Some of them still do housework but less than before. Others stopped because of their health. Others mentioned that walking was not understood as an activity for itself without another purpose. Some of them wondered where they should walk to as this is not commonly accepted in the Bedouin community.

'I like to work and move in the house, but I can't go out, I can't do it'

(women, 54, interview 8).

Other women showed how they adapted the social restrictions and tried to use space to walk.

'I don't do exercise but I walk around the house, sometimes I walk to the clinic....and I do housework' (Married woman, 40, interview 10).

'When I feel well I will walk around the house and this makes me feel good'
(Group 1, married woman, 50s, diabetic).

'I walk around the house... I don't rest I move all the time, because of that I feel I'm light' (Group 1, married woman, 50s, diabetic).

A young woman from the natural group explained how exercise affects the body and the emotions.

'Exercise strengthens the muscles and will make you energetic and light'
(group 1, unmarried woman, 20s, daughter of a diabetic patient).

Another young woman in a group interview thought the same.

'People who have diabetes should walk... move and do exercise' (Group 2, married woman, 20s).

One woman explained how the changes in her lifestyle from sheep herding to housework affected her.

'I don't work much at home like in the past. If I feel bad I will not do anything, I used to have sheep and go out with them, but now my feet are hurting and I can't do that anymore' (Married women, 64, interview 14)

Walking was understood as good exercise and women did walk to the clinic, local municipality, welfare services and go shopping. But walking as a leisure activity for improving one's health without an aim such as going to the bank was not undertaken.

'I don't do exercise. I just walk sometimes when I go to the clinic or the town' (Women, 54, interview 16)

This woman was among the young group of women I interviewed, she emphasized that she works as a young healthy woman and she does all the housework without help from her daughters.

'I work a lot in the house... I work like a young girl... I do everything by myself but I don't go walking except if I go to the city' (Widow, 48, interview 17)

Another woman said:

'I do massive amounts of housework but I don't do any exercise' (Group 2, I, late 30s)

In contrast men walked more as part of their social activities or they would walk specifically with the intent of exercising and see it as a 'good thing' to help manage their diabetes.

'Walking is a good thing, last year I had fat in my blood and I used to walk a lot and this brought down my fats, and now I would walk but I can't' (Married man, 55, interview 20)

'I try to walk everyday... I walk to the men's guest tent (shiq)' (Married man, 74, interview 26)

'I walk every day to the entrance of the village and I will continue doing that' (Married man, 56, interview 30)

'Walking is a good thing for people who have diabetes, this makes them sweat. To be active is better for any person. Sitting down all the time brings illness' (Married man, 52, interview 1)

'Walking is really good; I try to walk as often as I can. Usually if the weather is not hot I walk to the mosque' (Married man, 70, interview 23)

Despite a conviction in the importance of exercise, another man did not do it as diabetes had slowed him down and he was less active than before because of getting older.

'Sport and exercise is good for diabetes but after I got diabetes I became less active and tired all the time' (Married man, 53, interview 21)

'Walking is good for the body, it moves the blood, but this is for those who are able to do it. I can't, I'm old and my legs hurt.' (Married man, 64, interview 25)

Men and women knew that walking was good for them but often had a reduced capacity for walking because of age, tiredness, pain or injury. There were different ideas about how exercise worked by 'making them sweat' (Married man, 52, interview 1), 'moved the blood' (Married man, 64, interview 25), 'brought down fats' (Married man, 55, interview 20). Some women talked about physical activities as acts of moving, but again only in the house.

'I move at home picking up things around the house, but I don't cook, my daughters cook' (Married woman, 49, interview 6)

'I don't sit down I move in the house all day' (Married woman, 40, interview 10)

Women mentioned that walking outside the home was not socially acceptable and that people would talk about them. As with the Bedouin custom of social eating, some of the patients saw the problem they had with exercise as problem with the

Bedouin way of life or views of what constituted acceptable behaviour in public.

They are all worried about what other people would think of them if they walked out on their own. One younger married woman in particular compared herself with Jewish people.

'We are not Jewish, I wish I could walk like them and that no one would talk'
(Married woman, 38, interview 15)

'Where can I go? If I walk, they will think I have gone crazy' (Married woman, 55, interview 22)

'The people will not leave me alone, they will start to talk' (Widow, 59, interview 13)

One woman said she tried to walk but stopped due to the social pressure.

'I had fat in my blood, the doctor told me that I should walk...I started walking but the people talked about me... I stopped it' (Group 2, 3, 30s)

Another young woman asked:

'How can we do exercise in our community?' (Group 2, 4, 20s)

In terms of modifying diet and lifestyle to control diabetes, these data show that there were gender differences amongst Bedouin men and women. Bedouin women with diabetes were restricted in their movements owing to ideas of what is socially acceptable to do outside the home. They hardly walked except occasionally to the clinic or to the nearby shop and their main source of exercise was housework.

Women tended to get diabetes in their late thirties or later during and after their

forties, which meant that they were less active at this age as their daughters did the housework. Usually they had had multiple pregnancies (average family size 8-10 children) which had left them overweight or obese.

Men on the other hand walked more in their daily lives in general and did not have the same social constraints. They also seemed to have more knowledge about the benefits of exercise. This might be because they are more exposed to the external world and it may also be because they speak Hebrew better than the women and could understand the clinic staff better as a result.

Health professionals expressed views that food and behaviour surrounding food were key factors linked to the poor management of diabetes.

'Their culture around food, many men told me that when invited; they can't refuse what they are served in food and drink, such as coffee or dried fruit. I don't know if they are shy to say I have diabetes. I don't feel they are shy. They don't take it in that diet and a lack of physical activity will kill them' (Clinic nurse, X).

'They buy the cheapest staples such as white flour, white sugar, all the carbohydrates, potatoes...' (Clinic Nurse T).

'Maybe the direct reason for this situation is what they eat. They eat and don't move, they eat and sleep. All these bad things happen amongst the Bedouin'. (Clinic Bedouin doctor, Dr D).

The views of the health professionals indicate an understanding that aspects of Bedouin diet are a problem for those with diabetes but show little knowledge of food preparation and consumption or cognisance of the constraints and socio-cultural norms of the Bedouin or of gender differences. The generic advice to eat lean meat and more vegetables and no sweet drinks and take more exercise is difficult to adopt within this socio-cultural and behavioural context and more difficult for women in particular as they have less control over their food and physical activity.

Conclusions

This chapter has addressed the research question ‘To what extent can the neo-materialist, materialist and socio-behavioural explanations of health inequalities extend understandings of the experiences and management of diabetes care of marginalised Bedouin in the Negev?’

In relation to the neo-materialist explanation of health inequalities, it is clear that the Bedouin in the Negev are socially disadvantaged as a marginal indigenous Arab minority within Israel, and that their social disadvantage is affected by government policies relating to land ownership, to settlement of the Bedouin, and the way in which resources are allocated by the State in relation to education and health provision. They are the least educated group in Israel with the poorest living conditions. In terms of the materialist explanation, although some of the Bedouin in the Negev live in villages or towns with running water and electricity, schools and clinics, many of them do not and therefore on a daily basis struggle with access to water, fuel, light, transport to schools and clinics and with high unemployment.

These material socio-economic circumstances of diabetes patients have been shown to affect visits to the clinics, buying medication, and general adherence and this was voiced by both Bedouin themselves and health professionals as part of their explanatory models of diabetes.

In terms of the socio-behavioural explanations of health inequalities, it is clear that both Bedouin and health professionals understand the importance of diet and exercise but that health professionals have not adapted their advice to the socio-cultural setting. They share an understanding of the physical symptoms of diabetes but the explanatory models of how the condition is caused differs with the health professionals focusing on changes in lifestyle and obesity related to diet and exercise, and the Bedouin recognising this but relating it as well to traumatic events. The idea that strong emotions can affect physical health was found also in Arcury et al's study (2005) on diabetes in North Carolina.

The gendered analysis revealed that women and men adapt differently to modifying their diet and physical activity. Men are more able to negotiate a more sugar free and fat free diet than women and can take physical exercise. Women were less able to modify their behaviour, owing to their social position, socio-cultural context and roles. These findings show that the socio-behavioural explanation of health inequalities can extend understandings of the explanatory models of diabetes of health professionals and Bedouin with diabetes and shows the importance of understanding the socio-cultural context and how behaviour is embedded within it.

Chapter 6

Discussion and Conclusions

This chapter focuses on how the research questions have been answered and discusses the theoretical and empirical contribution to knowledge of this research study. Additionally, it will discuss the limitations, recommendations and suggestions for future research. It will also address the third research question. The study was located in two settings where Bedouin diabetic patients in the Negev received primary and secondary care. It was a multi-method case study involving an analysis of primary medical records to gain demographic, health and morbidity indicators; non-participant observation in a Health Centre and the Hospital Diabetic Outpatient Clinic undertaken during 5 months and semi structured interviews with patients and health professionals interviews carried out in the clinics and within households.

This chapter is a discussion of findings in relation to the research questions of this thesis which are as follows:

To what extent can a rights based approach in terms of quality availability, accessibility and acceptability extend understandings of health and health care provision to marginalised Bedouin in the Negev, Israel who have diabetes?

To what extent can the neo-materialist, materialist and socio-behavioural explanations of health inequalities extend understandings of

How generalisable to Bedouin in the Arab world and other indigenous peoples is the situation of Negev Bedouin with diabetes in terms of health care and experiences of living with the condition?

Original conceptual contribution

This case study of the Bedouin in the Negev living with diabetes can be seen as part of the wider scholarship on the rights to health of indigenous peoples or of Bedouin in the Middle East. It also is a case study of health inequalities of a socially disadvantaged minority group in a middle income country where the neo-materialist, materialist and socio-behavioural explanations have relevance and the explanatory models of illness held by Bedouin and health professionals make sense of their experiences with diabetes and their health care provision.

The first research question was:

To what extent can a rights based approach in terms of quality availability, accessibility and acceptability extend understandings of health and health care provision to marginalised Bedouin in the Negev, Israel who have diabetes?

A rights based approach to health care is based on the UN Special Comment 14. There is a need for empirical case studies of AAAQ in different settings (Yassin 2008) which this thesis can add to. Conceptually the rights to health framework applied in this setting identified how health care provision to the Bedouin in the Negev with diabetes had shortcomings in terms of quality, availability, accessibility,

acceptability and was to some extent discriminatory. The particular shortcomings were in terms of number of staff, quality of care including medical records, consultations and attitudes, hours of delivery, communication, inappropriate and unclear recommendations. It is an example of how the health care providers were functioning to what they considered to be the best of their abilities within a health care system that was not adapted to the needs of the patients and was offering minimum care. This is a situation which is not unique to the Bedouin in Israel but possibly similar to other Bedouin settings or rural health care settings. Yet within Israel, it was clear that other rural settings had more staff and did not have the same cultural and linguistic barriers between providers and patients. The AAAQ framework is a way to monitor provision and capture improvements over time. It also is a way to pinpoint both strengths and weaknesses and can be adapted for strengthening health systems by providers or governments were interested to do so as pointed out by the UN Special Rapporteur on the Right to Health (Hunt 2008). The use of this conceptual framework means that this case study is comparable with other case studies and is unique in its focus on a non-communicable disease, and the provision to a marginalised minority.

Although there was some Bedouin staff who were familiar with the culture and language, many health professionals lacked this and this affected care.

To what extent can the neo-materialist, materialist and socio-behavioural explanations of health inequalities extend understandings of health and health care provision to marginalised Bedouin in the Negev, Israel who have diabetes?

The neo-materialist and materialist explanations of health inequalities (Bartley 2004) argue that structural factors such as state policies are unequal in regard to education, health provision, access to land and employment and that social disadvantage both in terms of individual and household poverty contribute to health inequalities. The Negev Bedouin are an example of an indigenous displaced marginalized ethnic minority within Israel, with the highest indicators of poverty, social disadvantage and deprivation and the lowest health indicators in the country which include the highest rate of diabetes. This association between their political and material circumstances and their physical health is clear and is understood by both the Bedouin themselves and the health professionals working amongst them. The socio-behavioural explanation of health inequalities foregrounds the socio-cultural context of people's lives along with the constraints of their situation. Whilst the explanatory models of both health professionals and Bedouin recognised that changing lifestyles and diet affected diabetes and its control, the health professionals blamed the Bedouin for their lack of adherence to their medicines and the recommendation. Conceptually the findings illustrated how explanatory models of illness as identified by Kleinman (1978) and further developed by Kleinman et al. (2006) could be used and linked to explanations of health inequalities. The explanatory models of illness of health professionals and Bedouin could be compared to identify similarities and differences and could be linked to neo-materialist, materialist and socio-behavioural explanations of health inequalities. This relates to notions of lay epidemiology (Bury, 1994 Davison et al, 1991). The Bedouin men and women were clear that there were difficulties in following advice

within their economic, and socio- behavioural constraints in relation to purchasing medicines, changing diet and levels of physical activity.

The gender differences in relation to Bedouin with diabetes were not only in terms of prevalence in that more women than men had diabetes and had higher rates of obesity (Chapter 4) but also that there were gender differences in being empowered and able to modify dietary intake and take physical exercise outside the home.

Explanatory models have been used to enhance communication between health care providers and patients but in this thesis they have been used differently. By combining the explanatory models with the explanations of health inequalities, understandings of the different stakeholders views of health inequalities and the reasons for them have been extended. This is an original conceptual contribution.

The third research question was:

How generalisable to Bedouin in the Arab world and other indigenous peoples is the situation of Negev Bedouin with diabetes in terms of health care and experiences of living with the condition?

Generalisability to Arabs and Bedouin

There is a very high prevalence of diabetes amongst Arabs in the Arab world as shown in Chapter 2. Some aspects of the empirical findings are relevant to them particularly in rural areas in terms of the gender differences in negotiating changes in diet and physical activity owing to the socio-cultural context and socio-behavioural norms. The language difficulties that existed in consultations between

Jewish health professionals and their Bedouin patients are not relevant to Arabs in Arab societies but often health professionals who are from cities may be sent to rural clinics for short periods lacking sympathy with their less educated patients and require training regarding their lifestyle, norms, diet, and gender differences (Chen 2010).

The findings and conceptual framework of this thesis are generalisable in some ways to Bedouin in other Arab countries such as Jordan and Lebanon and possibly Syria (prior to the current hostilities). The rights to health framework identified a lack of quality and issues of availability, accessibility and acceptability including discriminatory care to a marginalized minority population. In Israel, the Bedouin in the Negev are part of the larger Arab minority and there is the added dimension of much of the health care provision being given by Jewish health professionals lacking Arabic with little knowledge of Arab or Bedouin society or lifestyle. This resulted in poor communication and health advice and recommendations which were not context appropriate. The health care provision was not adapted for Bedouin and the approach of some of the staff was to blame the Bedouin for lack of adherence to taking medicine and modifying their diet and exercise. Health care provision to Bedouin in Jordan and Lebanon has recently been shown to have shortcomings in terms of the attitudes of non-Bedouin health professionals and the quality of care in clinics serving Bedouin in these countries in general (Hasna et al. 2010, Lewando Hundt et al. 2012, Chatty et al. 2013, Al Kak 2011, Mansour 2011, Chatty 2011). These studies did not focus on diabetes care. This indicates that the position of Bedouin as a marginalized minority within Arab countries as well as within Israel,

results in similar shortcomings in their health care provision. There is one study from Saudi Arabia (Al-Nozha, 2004) which reviews differences in diabetes prevalence between rural and urban areas which would include Bedouin within the rural areas. There are other studies on diabetes care in Arab countries (Al-Nozha 2004, Gunaid 2002, Jaber et al. 2003) but they are bio-medical and are not focused on aspects of health care provision or health inequalities.

Indigenous people

The Bedouin are similar to other indigenous people in having high levels of diabetes as a consequence of a rapid change in lifestyle and changes in diet around the world. These include the Pima Indians in Arizona, USA (Smith, Manahan et al. 1993; Ravussin, Valencia et al. 1994; Krosnick 2000 ; Williams 2001), First Nation peoples in Australia and Canada (Daniel and Gamble 1995 ; Macaulay, Harris et al. 2003; Bisset, Cargo et al. 2004), and the Maori in New Zealand (Leonard, McDermott et al. 2002 ; Simmons and Voyle 2003), who live in poverty, are politically marginalized, have high rates of obesity and non-communicable diseases and lack of exercise. Evidence from other research studies shows the interventions to control diabetes need to combine a focus on diet with exercise and be adapted for the specific cultural context such as the one described amongst the Maoris in New Zealand (Simmons and Voyle 2003).

Original Empirical contribution

This research study makes an empirical contribution since there has been no other qualitative research observing diabetic patients' consultations with health care teams in the Negev Bedouin health clinics. In addition, there has been no research exploring the health professionals and Bedouin patients and their families' views and practices in the management and treatment of diabetes.

The findings revealed contradictory attitudes and lack of communication between the primary and the secondary care providers. The findings showed also different views and attitudes in the Health Centre about the diabetes situation and the way it should be treated.

There was a lack of communication between the health professionals in primary health care and the secondary health care. The professionals in the Health Centre did seem to think it was necessary to refer patients to secondary care, when they had difficulties in managing their diabetes or had diabetes complications. They claimed they had comprehensive medical knowledge concerning how to treat diabetes and that they were the best to deal with diabetic Bedouin patients. They did not believe that the secondary care staff had more tools and knowledge to deal with these situations. They blamed the patients when their diabetes was uncontrolled and for the increasing rate of diabetes amongst the Bedouin population. In contrast, the health professionals in the diabetic outpatient clinic showed a more extensive knowledge about the diabetes situation amongst the Negev Bedouin. They were concerned about the severity of the situation at present and in the future. They were

alarmed and called for immediate action to deal with the diabetes situation in the Bedouin community before it was too late. In addition, in secondary care they talked more about holistic ways to tackle the situation compared to the staff who worked in primary care. In the primary care clinic, the staff focused only on the patient, and more specifically emphasised medication and diet as the main obstacles to any effective treatment programme with each patient.

Understanding the daily management of diabetes requires spending a longer time with patients in the quarterly-review of diabetes. Although the Health Centre staff were trying to carry out an appointment system for the reviews, the work routine in the health centre did not allow them to spend more than a few minutes with each patient when they arrived at the clinic. The nurse spent time with the patient only for taking basic diabetic measures such as the finger blood glucose test, blood pressure, and sometimes height and weight. There was no time to talk with patients about their diabetes or to make comprehensive assessments about the current situation, such as looking at blood and urine tests and referring to an optometrist as well as deciding what should be done in the short term and long term.

Also there was lack of assessment and follow up of the use of self-monitoring machines when they were given out to many of the patients and no discussion about what to do about the results. None of the patients brought their self-readings results although a few of them mentioned they checked their blood sugar sometimes at home. Some of the women mentioned that they did not know how to use the machine and that no one in their family knew how to do it.

Bedouin patients and their families' members had their own explanatory models about the onset of the diabetes which were gender specific. Women perceived this as happening owing to sad or traumatic events. . Some women related it to their experiences of being diabetic in pregnancy. Men felt that it had happened owing to aspects of their lifestyle, in particular the consumption of sweet foods. The signs of diabetes were predominantly experienced and explained as related to feeling tired, faint, dizzy, having painful feet or headaches and changes in their vision which meant that they were unable to carry out usual activities.

Bedouin usually used medical terms when they talked about their diabetes. They used the term of bringing diabetes into balance when they meant to keeping blood sugar at a normal level. Also they used the term 'uncontrolled' when they talked about sugar levels being high. Many Bedouin mentioned diet and exercise when asked about ways manage diabetes. The two things they kept mentioning were not to eat food containing high amounts of fat and drinks with high amount of sugar. They did not mention anything about vegetables or fruits or other types of food.

There were gender differences in the management of diabetes. Patients understood that sweet food or drinks were bad for their condition, but women did not feel able to refuse food and drink whereas those men felt more empowered to do so. This was a reflection of their different social status.

Regarding physical activities men had more opportunities to take exercise and spent more time outside the home. Socially it was not accepted that women walk outside the home without a task related purpose. Therefore gender was revealed as important

and relevant in the management of diabetes and needs to be considered when planning community interventions.

Limitations

There are a number of limitations to this study. It does not include the views of men from natural group interviews. I was unable to carry these out myself and further individual household interviews would have strengthened the data set. Research was not carried out in clinic located in the unrecognised villages and therefore there lacked of the views of health professionals working there but some of the household interviews were located in unrecognised villages. I did not manage to interview patients in the diabetic outpatient clinic who had been referred from the health centre, during the period I carried out the research. I did not manage to see a doctor or nurse discussing a new diagnosis of diabetes with a patient.

Recommendations

Overall, there is a lack of appropriate care to Bedouin with diabetes. The following recommendations pertain to the Negev setting in Israel but could be relevant (apart from the Arabic language) to health care professionals working with Bedouin in other Arab countries. The recommendations are relevant to health care provision for all Bedouin with diabetes in Arab countries as well as Israel.

- All health professionals should be aware of comprehensive practical guidelines and to keep medical records of adequate standard

- Health staff require more time and staffing to work with Bedouin patients and link workers based in the clinic could improve communication with patients
- Non Bedouin health professionals should have professional development regarding Bedouin culture, beliefs and lifestyle when they start work with the Bedouin and consider how this affects their consultations and advice to patients
- Non Arabic speakers should be given colloquial Arabic training or have interpreters through clinic based link workers
- There is a need for intensive gendered community health programmes to raise the awareness of diabetes and its risks could be implemented. It could be delivered through schools, mosques, clinics and community centres. The gender sensitive community based interventions concerning diet and exercise such as women only exercise classes, and organised walking groups with female leaders and weight watcher support groups

In conclusion this mixed method case study of health care provision and living with diabetes amongst the Negev Bedouin, a marginalized Arab indigenous minority group in Israel, has made an original empirical and conceptual contribution to knowledge. Empirically the study has focused on older people with a chronic disease

which is endemic within the Arab world in a rural disadvantaged context and has explored dimensions of both health care provision and experiences of living with diabetes which has gender specific aspects. Clearly there are some aspects of the findings that are specific to the Israeli context.

Conceptually, the right to health framework as developed from UN Special Comment 14 on AAAQ has been utilised as a lens to analyse health care provision and explanations of health inequalities have been linked to explanatory models of illness of health care providers and Bedouin showing the importance and relevance of lay epidemiology.

The findings both empirically and conceptually are of relevance to health care providers and patients with diabetes elsewhere in the Arab world and to indigenous peoples with diabetes and those who care for them.

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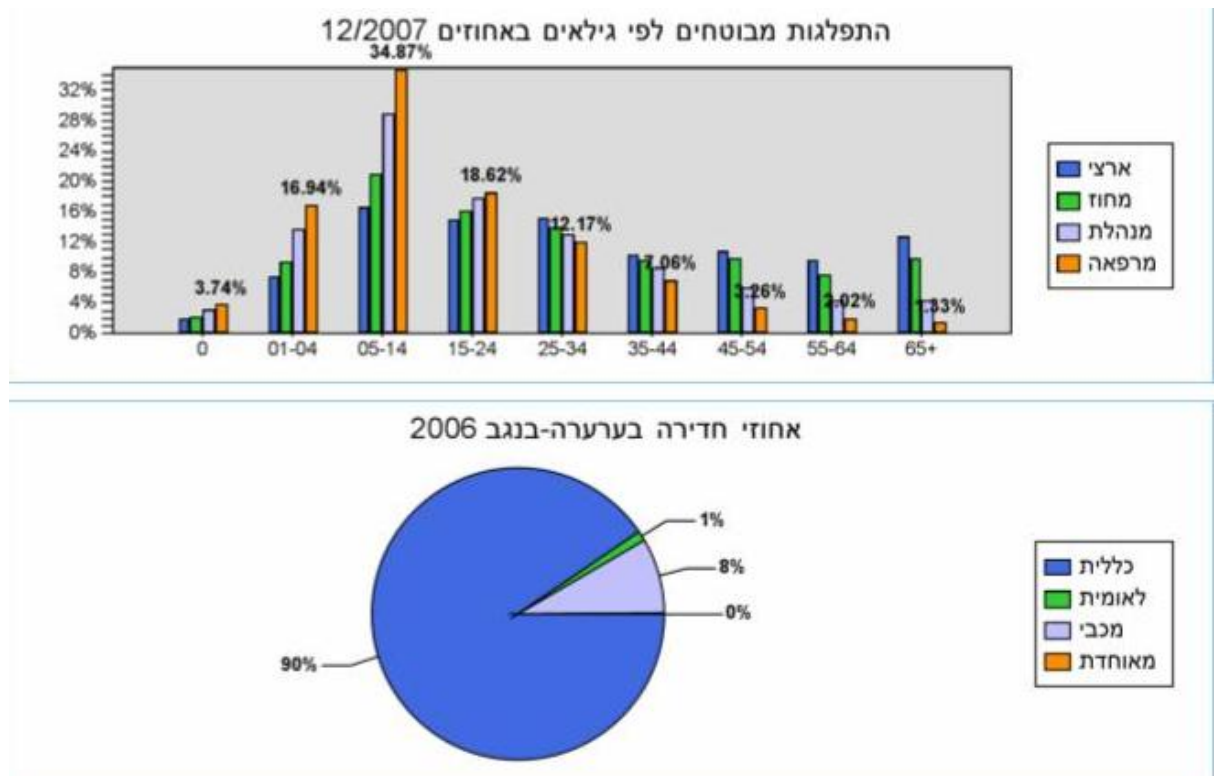
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Appendices

Appendix A: Percentages distribution of insured costumers in General Health

Services fund by age December 2007



Source: health centre documentation

Appendix B: Wikipedia Manual of Style Arabic

Consonants

Arabic	Name	Standard translit.	Strict translit.	Notes
ب	bā'	b	b	
ت	tā'	t	t	
ث	thā'	th	th	the sequence <th> is written t'h
ج	jīm	j	j	pronounced [g] in Egyptian Arabic
ح	hā'	h	ḥ	
خ	khā'	kh	kh	the sequence <kh> is written k'h
د	dāl	d	d	
ذ	dhāl	dh	dh	the sequence <dh> is written d'h
ر	rā'	r	r	
ز	zāy	z	z	
س	sīn	s	s	
ش	shīn	sh	sh	the sequence <sh> is written s'h
ص	ṣād	s	ṣ	
ض	ḍād	d	ḍ	
ط	ṭā'	t	ṭ	
ظ	ẓā'	z	ẓ	
ع	'ayn	ʿ	ʿ	different from hamza
غ	ghayn	gh	gh	
ف	fā'	f	f	
ق	qāf	q	q	sometimes transliterated as "g"
ك	kāf	k	k	
ل	lām	l	l	
م	mīm	m	m	
ن	nūn	n	n	
ه	hā'	h	h	
ء	hamzah	ʾ	ʾ	omitted in initial position ^[1]
آ	tā' marbūṭah	a or at or atan	ah or at or atan	usually as ah , but sometimes as at or atan . ^[2]
و	wāw	w	w	See also long vowels
ي	ya'	y	y	See also long vowels
ي	(yā')	iy or i	īy or ī	romanized īy except in final position ^[3]
أ	'alif maddah	a, 'a	ā , 'ā	Initially ā , medially 'ā

Appendix C: ALA-LC Romanization Arabic Style (American Library Association-
Library of Congress)

Arabic				
Letters of the Alphabet				
Initial	Medial	Final	Alone	Romanization
ا	ا	ا	ا	omit (see Note 1)
ب	ب	ب	ب	b
ت	ت	ت	ت	t
ث	ث	ث	ث	th
ج	ج	ج	ج	j
ح	ح	ح	ح	h
خ	خ	خ	خ	kh
د	د	د	د	d
ذ	ذ	ذ	ذ	dh
ر	ر	ر	ر	r
ز	ز	ز	ز	z
س	س	س	س	s
ش	ش	ش	ش	sh
ص	ص	ص	ص	ṣ
ض	ض	ض	ض	ḍ
ط	ط	ط	ط	t
ظ	ظ	ظ	ظ	z
ع	ع	ع	ع	' (ayn)
غ	غ	غ	غ	gh
ف	ف	ف	ف	f (see Note 2)
ق	ق	ق	ق	q (see Note 2)
ك	ك	ك	ك	k
ل	ل	ل	ل	l
م	م	م	م	m
ن	ن	ن	ن	n
هـ	هـ	هـ ، هـ	هـ ، هـ	h (see Note 3)
و	و	و	و	w
ي	ي	ي	ي	y
Vowels and Diphthongs				
ā	a	ā	ā (see Rule 5)	ī
ū	u	ū	ū (see Rule 6(a))	aw
i	i	ī	ī	ay

Letters Representing Non-Arabic Consonants

This list is not exhaustive. It should be noted that a letter in this group may have more than one phonetic value, depending on the country or area where it is used, and that the romanization will vary accordingly.

گ	g	چ	ch	ف	v
ڭ	G	چ	zh	ڦ	v
پ	P	ژ	zh	ڤ	v

Notes

1. For the use of *alif* to support *hamzah*, see rule 2. For the romanization of *hamzah* by the consonantal sign ' (alif), see rule 8(a). For other orthographic uses of *alif* see rules 3-5.
2. The *Maghribī* variations ڤ and ڦ are romanized *f* and *q* respectively.
3. *ō* in a word in the construct state is romanized *t*. See rule 7(b).

RULES OF APPLICATION

Arabic Letters Romanized in Different Ways Depending on Their Context

1. As indicated in the table, و and ي may represent:

- (a) The consonants romanized *w* and *y*, respectively.

wad'	وضع
'iwaḍ	عوض
dalw	دلو
yad	يد
ḥiyal	حيل
ṭahy	طهي

- (b) The long vowels romanized *ū*, *ī*, and *ā* respectively.

ūlá	اولى
ṣūrah	صورة
dhū	ذو
īmān	ايمان
īl	جيل
fī	في
kitāb	كتاب
saḥāb	سحاب
jumān	جمان

See also rules 11(a) and 11(b)(1-2).

(c) The diphthongs romanized *aw* and *ay*, respectively.

awj	اوج
nawm	نوم
law	لو
aysar	ايسر
shaykh	شيخ
'aynay	عيني

See also rules 11(a)(2) and 11(b)(3).

2. | (*alif*), 9 and ى when used to support َ (*hamzah*) are not represented in romanization. See rule 8(a).

3. | (*alif*) when used to support *waslah* (ِ) and *maddah* (َ) is not represented in romanization. See rules 9 and 10.

4. | (*alif*) and 9 when used as orthographic signs without phonetic significance are not represented in romanization.

fa'alū	فعلوا
ulā'ika	اولائك
'ilman wa-'amalan	علما وعملا

See also rule 12 and examples cited in rules 23-26.

5. | (*alif*) is used to represent the long vowel romanized *ā*, as indicated in the table.

fā'il	فاعل
riḡā	رضا

This *alif*, when medial, is sometimes omitted in Arabic; it is always indicated in romanization. See rule 19.

6. Final ى appears in the following special cases:

(a) As ى (*alif maqṣūrah*) used in place of ِ to represent the long vowel romanized *ā*.

ḡattá	حتى
maḡdá	مضى
kubrá	كبرى
Yahyá	يحيى
musammá	مسمى
Muṡṡafá	مصطفى

(b) As ى in nouns and adjectives of the form *fāʔ* which are derived from defective roots. This ending is romanized *ī*, not *iy*, without regard to the presence of ِ (*shaddah*). See rule 11(b)(2).

Raḍī al-Dīn

رضى الدين

Compare the *fa'īl* form of the same root الرضى [without *shaddah*] *al-Raḍī*.

- (c) As رضى in the relative adjective (*nisbah*). The ending, like (b) above, is romanized *t*, not *īy*.

al-Miṣrī

المصري

Compare المصرية *al-Miṣrīyah* and see rule 11(b)(1).

7. *ō* (*tā' marbūṭah*)

- (a) When the noun or adjective ending in *ō* is indefinite, or is preceded by the definite article, *ō* is romanized *h*. The *ō* in such positions is often replaced by *o*.

ṣalāh

صلاة

al-Risālah al-bahīyah

الرسالة البهية

mir'āh

مرآة

Urjūzah fī al-tibb

ارجوزة في الطب

- (b) When the word ending in *ō* is in the construct state, *ō* is romanized *t*.

Wizārat al-Tarbiyah

وزارة التربية

Mir'āt al-zamān

مرآة الزمان

- (c) When the word ending in *ō* is used adverbially, *ō* (vocalized *ō*) is romanized *tan*.

See rule 12(b).

Romanization of Arabic Orthographic Symbols Other than Letters and Vowel Signs

The signs listed below are frequently omitted from unvocalized Arabic writing and printing; their presence or absence must then be inferred. They are represented in romanization according to the following rules:

8. *ḥ* (*hamzah*)

- (a) In initial position, whether at the beginning of a word, following a prefixed preposition or conjunction, or following the definite article, *ḥ* is not represented in romanization.

When medial or final, *ḥ* is romanized as ' (alif).

asad

أسد

uns

أنس

idha

إذا

mas'alah

مسألة

mu'tamar

مؤتمر

dā'im

دائم

mala'a

ملاً

khaṭī'a

خطئ

(b) c , when replaced by the sign c (*waṣlah*) and then known as *hamzat al-waṣl*, is not represented in romanization. See rule 9 below.

9. c (*waṣlah*), like initial c , is not represented in romanization. See also rule 8(b) above. When the *alif* which supports *waṣlah* belongs to the article ال , the initial vowel of the article is romanized *a*. See rule 17(b). In other words, beginning with *hamzat al-waṣl*, the initial vowel is romanized *i*.

Riḥlat Ibn Jubayr	رحلة ابن جبير
al-istidrāk	الأستدراك
kutub iqṭanat'hā	كتب أقتتها
bi-ihtimām 'Abd al-Majīd	بأهتمام عيد المجيد

10. ā (*maddah*)

(a) Initial ā is romanized *ā*.

ālah	آلة
Kullīyat al-Ādāb	كلية الآداب

(b) Medial ā , when it represents the phonetic combination 'ā, is so romanized.

ta'ālif	تأليف
ma'āthir	مآثر

(c) ā is otherwise not represented in romanization.

khulafā'	خلفاء
----------	-------

11. āw (*shaddah* or *tashdīd*)

(a) Over w :

(1) āw , representing the combination of long vowel plus consonant, is romanized *ūw*.

adūw	عدو
qūwah	قوة

See also rule 1(b).

(2) āw , representing the combination of diphthong plus consonant, is romanized *aww*.

Shawwāl	شَوَّال
ṣawwara	صَوَّر
jaww	جَوَّ

See also rule 1(c).

(b) Over ي:

(1) Medial يَ , representing the combination of long vowel plus consonant, is romanized *īy*.

al-Miṣrīyah المِصْرِيَّة

See also rule 1(b).

(2) Final يَ is romanized *ī*. See rules 6(b) and 6(c).

(3) Medial and final يَ , representing the combination of diphthong plus consonant, is romanized *ayy*.

ayyām أَيَّامٌ
sayyid سَيِّدٌ
Quṣayy قِصَى

See also rule 1(c).

(c) Over other letters, يَ is represented in romanization by doubling the letter or digraph concerned.

al-Ghazzī الْغَزِّيُّ
al-Kashshāf الْكَشَّافُ

12. *Tanwīn* may take the written form و , وْ (وِ), or وِ , romanized *un*, *an*, and *in*, respectively. *Tanwīn* is normally disregarded in romanization, however. It is indicated in the following cases:

(a) When it occurs in indefinite nouns derived from defective roots.

qāḍīn قَاضٍ
ma'nān مَعْنٍ

(b) When it indicates the adverbial use of a noun or adjective.

ṭab'an طَبَعًا
faj'atan فَجْأَةً
al-Mushtarik waḍ'an الْمَشْتَرِكُ وَضْعًا
wa-al-muftariq ṣuq'an وَالْمُفْتَرِقُ صَقْعًا

Grammatical Structure as It Affects Romanization

13. Final inflections of verbs are retained in romanization, except in pause.

man waliya Miṣr مِنْ وَلى مِصْرَ
ma'rifat mā yajibu la-hum مَعْرِفَةَ مَا يَجِبُ لَهُمْ
ṣallā Allāh 'alayhi wa-sallam صَلَّى اللهُ عَلَيْهِ وَسَلَّمَ
al-Lu'lu' al-maknūn fī ḥukm اللُّؤلؤُ الْمَكْنُونُ فِي حُكْمِ
al-akhbār 'ammā sayakūn الْاِخْبَارِ عَمَّا سَيَكُونُ

14. Final inflections of nouns and adjectives:
- (a) Vocalic endings are not represented in romanization, except preceding pronominal suffixes, and except when the text being romanized is in verse.
- | | |
|------------------------------|-----------------------------|
| Ma'had Mawlāya al-Ḥasan | معهد مولاي الحسن |
| uṣūluhā al-nafsiyah wa-ṭuruq | اصولها النفسية وطرق تدريسها |
| tadrīsihā | |
| ilā yawminā hādhā | الى يومنا هذا |
- (b) *Tanwīn* is not represented in romanization, except as specified in rule 12.
- (c) *ō* (*tā' marbūṭah*) is romanized h or t as specified in rule 7.
- (d) For the romanization of the relative adjective (*nisbah*) see rule 6(c).
15. Pronouns, pronominal suffixes, and demonstratives:
- (a) Vocalic endings are retained in romanization.
- | | |
|----------------------------|-------------------|
| anā wa-anta | انا وانت |
| hādhīhi al-ḥāl | هذه الحال |
| mu'allafātuhi wa-shurūḥuhā | مؤلفاته وشروحاتها |
- (b) At the close of a phrase or sentence, the ending is romanized in its pausal form.
- | | |
|---------------------------|-----------------------------|
| ḥayātuhu wa-'aṣruḥ | حياته وعصره |
| Tawfiq al-Ḥakīm, afkāruḥ, | توفيق الحكيم، أفكاره، آثاره |
| āthāruḥ | |
16. Prepositions and conjunctions:
- (a) Final vowels of separable prepositions and conjunctions are retained in romanization.
- | | |
|---------------|----------|
| anna | ان |
| annahu | انه |
| bayna yadayhu | بين يديه |
- Note the special cases: مما *mimmā*, ممن *mimman*.
- (b) Inseparable prepositions, conjunctions, and other prefixes are connected with what follows by a hyphen.
- | | |
|-----------|--------|
| bi-hi | به |
| wa-ma'ahu | ومعه |
| lā-silkī | لاسلكى |
17. The definite article:
- (a) The romanized form *al/* is connected with the following word by a hyphen.
- | | |
|-------------------|---------------|
| al-kitāb al-thānī | الكتاب الثاني |
| al-ittiḥād | الاتحاد |
| al-aṣl | الاصل |
| al-āthār | الآثار |

- (b) When **ال** is initial in the word, and when it follows an inseparable preposition or conjunction, it is always romanized *a/* regardless of whether the preceding word, as romanized, ends in a vowel or a consonant.

ilá al-ān	الى الآن
Abū al-Wafā'	ابو الوفاء
Maktabat al-Nahḍah al-Miṣrīyah	مكتبة النهضة المصرية
bi-al-tamām wa-al-kamāl	بالتمام والكمال

Note the exceptional treatment of the preposition **ل** followed by the article:

lil-Shirbīnī	للشربيني
--------------	----------

See also rule 23.

- (c) The **ل** of the article is always romanized *l/* whether it is followed by a "sun letter" or not, i.e., regardless of whether or not it is assimilated in pronunciation to the initial consonant of the word to which it is attached.

al-ḥurūf al-abjadīyah	الحروف الابجدية
Abū al-Layth al-Samarqandī	ابو الليث السمرقندي

Orthography of Arabic in Romanization

18. Capitalization:

- (a) Rules for the capitalization of English are followed, except that the definite article *a/* is given in lower case in all positions.
- (b) Diacritics are used with both upper and lower case letters.

al-Īrī	الايحيى
al-Ālūsī	الآلوسى

19. The macron or the acute accent, as appropriate, is used to indicate all long vowels, including those which in Arabic script are written defectively. The macron or the acute accent, as the case may be, is retained over final long vowels which are shortened in pronunciation before *hamzat al-waṣl*.

Ibrāhīm	ابراهيم ، ابرهيم
Dā'ūd	داؤود ، داؤد
Abū al-Ḥasan	ابو الحسن
ru'ūs	رؤس
dhālika	ذلك
'alá al-'ayn	على العين

20. The hyphen is used:

- (a) To connect the definite article *a/* with the word to which it is attached. See rule 17(a).
- (b) Between an inseparable prefix and what follows. See rules 16(b) and 17(b) above.

(c) Between *bin* and the following element in personal names when they are written in Arabic as a single word. See rule 25.

21. The prime (') is used:

(a) To separate two letters representing two distinct consonantal sounds, when the combination might otherwise be read as a digraph.

Ad'ham	أدهم
akramat'hā	أكرمتهَا

(b) To mark the use of a letter in its final form when it occurs in the middle of a word.

Qal'ah'jī	قلعة جِي
Shaykh'zādah	شيخ زاده

22. As in the case of romanization from other languages, foreign words which occur in an Arabic context and are written in Arabic letters are romanized according to the rules for romanizing Arabic.

Jārmānūs (<i>not</i> Germanos <i>nor</i> Germanus)	جارمانوس
Lūrd Ghrānfil (<i>not</i> Lord Granville)	لورد غرانفيل
Īsāghūjī (<i>not</i> Isagoge)	ايساغوجي

For short vowels not indicated in the Arabic, the Arabic vowel nearest to the original pronunciation is supplied.

Gharsiyā Khayin (<i>not</i> García Jaén)	غرسيا خين
---	-----------

Examples of Irregular Arabic Orthography

23. Note the romanization of الله, alone and in combination.

Allāh	الله
billāh	بِالله
lillāh	لله
bismillāh	بِسْمِ الله
al-Mustanṣir billāh	المستنصر بالله

24. Note the romanization of the following personal names:

Ṭāhā	طه
Yāsīn	يس ، يسن
'Amr	عمرو
Bahjat	بهجت ، بهجة

25. ابن and بن are both romanized *ibn* in all positions.

Aḥmad ibn Muḥammad ibn Abī al-Rabi'	أحمد بن محمد بن أبي الربيع
Sharḥ Ibn 'Aqīl 'alā Alfīyat Ibn Mālik	شرح ابن عقيل على الفية ابن مالك

Exception is made in the case of modern names, typically North African, in which the element *بن* is pronounced *bin*.

Bin Khiddah	بن خده
Bin-'Abd Allāh	بنعبد الله

26. Note the anomalous spelling *مائة*, romanized *mi'ah*.


Appendix D: Yearly summary of diabetes nurses' reviews, 06/02/2006-06/02/2007

מס'מח: מרפאת פרזיט
סמל: דרום

סיכום ביצוע מעקב סוכרת

בטוח תאריכים: 06/02/2006 - 06/02/2007
הוסף על ידי: נעמה אבו-מעמר

סיכום מרפאתי:

BMI	מטקל	ריגלים	ל.דם	מכורח	CREATIN	TG	CH-LDL	חלבון בשתן המדידה	HBA1C	GLUCOSE	צם מטקב שלם	סטי"כ חולי סוכרת
25	109	186	162	0	150	161	160	63	101	102	0	
33.26	88.69	86.90	96.43	0.00	94.66	95.83	95.24	37.90	95.85	96.43	0	%מוכלל חולי סוכרת

Page 1 of 1

סיכום ביצוע מעקב סוכרת

9999 אבו-מעמר

Appendix E: guidelines for newly diagnosed diabetes patients -Nurse Letter from health centre-

מנהלת נגב דרומי
טלפון : 08-6254202
פקס : 08-6254237

1 בנובמבר 2004

הנדון: סדנת המשך טיוב הטיפול בחולים כרוניים תוכנית הדרכה לחולה חדש

פגישה ראשונה

מטרות -
הכרות אישית והדדית.
יצירת חווה טיפולי.
בחירת המטופל את המטפל והטיפול.
המטופל יצא עם ידע בסיסי.

מהלך -
נדבר על איך נעבוד ביחד (חווה) -
1. מה היית רוצה?
2. ברמה כללית לבנות ציפיות / מטרות
3. מה אתה מוכן לעשות שזה יצליח
4. האם יש בקשות מיוחדות ממני
5. האם אתה רוצה לערב עוד מישהו בתהליך הטיפול
6. הנחת תשתית ליצירת קשר טיפולי
7. חשיפה לידע בסיסי רלוונטי
8. לסיים את המפגש במשימה קטנה למטופל.

פגישה שנייה

מטרה -
בניית תוכנית טיפולית מיטבית המתאימה להרגלי המטופל ולאופן העבודה במרפאה מוסכמת
עיי שני הצדדים. *כנול - ואני כנול ואני הנציים*

מהלך -
השלמת מידע על התמודדות וקשיים
על מנת להגדיר מטרות טיפוליות
לשאול מה היית רוצה שישתנה בעקבות הטיפול
מה מפריע לך בעקבות המחלה
מתוך זה להגדיר את המטרות במונחים של מה שמפריע לו בשפה שלו.
תוכנית טיפולית - טיפול תרופתי
תזונה - (חשוב שחלק מהרעיונות בתזונה יהיו שלו).
פעילות גופנית - מותאמת.
תוך שיתוף ומעורבות של המטופל.
1. מה אתה מציע?
2. מה אתה חושב?
3. איך נכון שאתה תעשה?
4. מה מתאים לך?

שומרים על בריאות כללית

שירותי בריאות כללית ♦ מחוז דרום ♦ מנהלת נגב דרומי ♦ טלפון 08-6254202 ♦ פקס 08-6254237

פגישה שלישית

פגישת מעקב -

מטרות - ביצוע מעקב והתאמתו בתוכנית האם המטופל הבין את תוכנית הטיפול האם המטופל עומד בתנאי החוזה. שיפור אובייקטיבי / סובייקטיבי.

מהלך -

פתיחה.

שאלות הרגשה כללית.

שאלות לגבי הטיפול.

ביצוע מעקב והתאמות בתוכנית בהתאם לצורך.

חיזוקים לגבי שינויים באורח החיים.

סיכום המפגש.

תוכנית המשך - 2 מטלות.

תיאום המפגש הבא.

מפגש הערכה

מטרה -

השגת הסכמה ביחס למידת הצלחת התהליך והתאמת אופן הטיפול והיעדים בהתאם לצורך.

מהלך -

שאלות פתוחות - מה אתה מרגיש לגבי התהליך.

שאלות כלליות:

1. מה השתפר מאז הטיפול

2. מה עובד, מה לא.

3. מה היית רוצה לשנות.

4. מה הצלחנו, מה לא

5. האם התקשורת בינינו עוזרת להתקדם

סיכמה : איילה עוזר.

שומרים על בריאות כללית

שירותי בריאות כללית ♦ מחוז דרום ♦ מנהלת נגב דרומי ♦ טלפון 08-6254202 ♦ פקס 08-6254237

Appendix F: Application form for Helinski Committee (Hebrew)

משרד הבריאות

אגף הרוקחות

ירושלים

התשס"ו-2006

כל הטפסים ימולאו בדפוס בלבד.

במילוי הטפסים אין לשנות את נוסח הסעיפים או להשמיטם. אם לדעת ממלא הטופס, סעיף מסוים אינו רלוונטי, ניתן למחוק הסעיף על-ידי העברת קו חוצה עליו ולציין את סיבת המחיקה.

במילוי הטפסים ניתן להוסיף שורות/דפים לפי הצורך כדי להרחיב את המידע הנדרש. במקרה זה יש למספר את דפי הטפסים באופן רציף.

יש למלא ולחתום על טופס רשימת המסמכים - CHECK LIST (טופס מספר 9).

טופס הבקשה (טופס מספר 1):

4.1 יש למלא את טופס הבקשה, בהתאם לסוג הניסוי (כמפורט בסעיף 21 בנוהל) בפירוט ובדייקנות.

4.2 תקציר הפרוטוקול יכתב בעברית או באנגלית והמידע יהיה זהה למידע שבפרוטוקול.

4.3 החוקר הראשי יחתום על הצהרת הרופא האחראי לניסוי. בנוסף, החוקר הראשי וחוקרי המשנה יחתמו על דף החתימות בסוף טופס הבקשה. בקשה שאינה חתומה לא תטופל ותוחזר לשולח.

טופס ההסכמה-מדעת (טפסים 2 ו-3):

5.1 בתחתית כל עמוד יופיע תאריך ומספר גרסה של הטופס.

5.2 בסעיף ד' יש לפרט את כל המידע על הניסוי הרפואי, לפי הנושאים המופיעים בסעיף זה, בעברית ובשפה קלה וברורה ועד כמה שאפשר, ללא מונחים רפואיים, כך שכל אדם יוכל להבין את תוכנו. יש להתחשב באוכלוסיית הניסוי ולהימנע מכתובת דברי הסבר ארוכים ומפותלים.

5.3 בכל מקום שמצוין מטופל או משתתף (בלשון זכר), הכוונה גם למטופלת או משתתפת.

קיימים מקרים בהם יש צורך לתרגם, לשפה אחרת מעברית, את טופס ההסכמה מדעת עבור המשתתפים בניסוי הרפואי. יוזם הניסוי ידאג מראש לתרגום ויזהיר בכתב כי התרגום נאמן למקור. החוקר יצרף את התרגום והצהרה למסמכי הבקשה.

במקרה שהמשתתף בניסוי או נציגו החוקי אינו מסוגל לקרוא את טופס ההסכמה מדעת, מחמת אי-ידיעת השפה או מחמת אי-יכולתו לקרוא, עד בלתי תלוי חייב להיות נוכח במשך ההסבר על מהות הניסוי הרפואי. לאחר שהמשתתף או נציגו החוקי הביע את הסכמתו בעל-פה להשתתפות בניסוי, העד יחתום על טופס ההסכמה, תוך ציון תאריך החתימה.

בניסויים רפואיים במקרי חירום (כמוגדר בנספח לנוהל), בהם נדרשת חתימה של רופא נוסף בלתי תלוי, יש להוסיף לטופס ההסכמה מדעת את שם הרופא, מספר הרישיון, חתימה ותאריך.

לפני כניסתו לניסוי הרפואי יקבל המשתתף או נציגו החוקי עותק מטופס ההסכמה במלואו, נושא תאריך וחתום כדין.

התחייבות היוזם (טופס מספר 4):

ההתחייבות תישא שתי חתימות, כדלקמן:

10.1 במקרה של יוזם-חברה מסחרית, היוזם יחתום על התחייבות זו והחוקר הראשי יאשרה בחתימתו. מנהל בית החולים או מי שהסמיכו, יחתום על נוסח התחייבות היוזם המצורף להסכם החוזי בין יוזם הניסוי למוסד הרפואי עם אישור חוזה ההתקשרות המסחרית.

10.2 במקרה של יוזם-חוקר, הוא יחתום על התחייבות זו, ומנהל בית החולים, או מי שהסמיכו, יאשרה בחתימתו.

התחייבות היוזם (טופס מספר 4) והצהרת יוזם הניסוי הרפואי (או נציגו בארץ) (טופס מספר 5) ישאו חתימה וחותמת של היוזם (או נציגו בארץ).

חייבת להיות זהות בין המסמכים שבידי חוקר לבין המסמכים שמוגשים לעיון ועדת הלסינקי המוסדית. במידה שנדרשו תיקונים במסמכי בקשה כלשהם, האישרים לניסוי (טפסים 6 ו-7) יכילו את פרטי המסמכים המעודכנים.

אם מדובר בניסוי רב-מרכזי בארץ, יש לרשום זאת בטופס מספר 6.

הדיווח השנתי על ניסויים רפואיים שאישר מנהל המוסד הרפואי (טופס מספר 15) יודפס על נייר מכתבים רשמי של אותו מוסד.

יש לצרף לכל בקשה נספח אבטחת מידע של אוניברסיטת בן-גוריון והמרכז הרפואי האוניברסיטאי סורוקה המופיע באתר זה.

אני החתום מטה מבקש לערוך את המחקר הרפואי המפורט בזה:

[1]

מספר הבקשה בוועדת הלסינקי (למילוי ע"י מזכירות הוועדה):	מספר הטלפון: 08-6400583
מספר הפקס: 08-6403531	מספר הבקשה (שם ומחלקה): דר' אילנה הרמן
מספר הבקשה (שם ומחלקה): ^[2]	מספר הבקשה (שם ומחלקה): דר' אילנה הרמן
מספר הבקשה (שם ומחלקה): ^[2]	מספר הבקשה (שם ומחלקה): דר' אילנה הרמן

^[1] מחקר רפואי, כולל: לקיחת דמים, שאלונים, מחקר אפידמיולוגי, מחקר בדגימות רקמה וכו', פרט למחקר גנטי.
^[2] חוקרי המשנה הרשומים כאן הם החוקרים החתומים על עמוד 4/4 של טופס זה

שם המוסד הרפואי: , מרכז רפואי אוניברסיטאי סורוקה	
נושא המחקר הרפואי: Indigenous people in context of modernity: management of diabetes amongst Bedouin in Israel	
פרוטוקול המחקר – מספר:	תאריך הפרוטוקול: 24.12.2006
טופס הסכמה – גרסה:	תאריך טופס ההסכמה: 24.12.2006
הניסוי יירשם במאגר הניסויים הרפואיים: כן - מספר הרישום יימסר לוועדת הלסינקי לאחר אישור הניסוי על-ידיה (טופס מס' 6). לא - פירוט הסיבה לאי-הרישום:	
מטרות המחקר הרפואי: Understand the problem of controlling of diabetes among the Negev Bedouin from the perspectives of both Bedouin patients and health care providers Analyse the barriers and enablers to personal self management of diabetes Identify appropriate community interventions for women and men to achieve better control of diabetes among Bedouin in the Middle East.	
שם יוזם המחקר וכתובתו: Ferial Alanoo School of Health and Social Studies University of Warwick Coventry CV4 7AL UK	מספר הטלפון: 00447770998487 מספר הפקס:

מספר הטלפון: מספר הפקס: שם איש הקשר:	שם נציג היוזם בארץ וכתובתו:
	לחוקר הראשי או לאחד מחוקרי המשנה יש זיקה ³³ אין זיקה ליוזם המחקר הרפואי. אם יש, פרט.
לא	כן
מתכונת המחקר הרפואי (לדוגמא: מחקר פתוח, השוואתי, מבוקר סמוי, מבוקר כפול סמיות, וכד') The research will be a case study	
תקציר פרוטוקול המחקר הרפואי, כולל: רציונל לביצוע המחקר, מספר המשתתפים במרכז זה, גיל, מין, קריטריונים להכללה, לאי-הכללה ולהוצאה מהמחקר, התייחסות להכללת אוכלוסיות מיוחדות – נשים בהריון, ילדים וחסרי כושר שיפוט, משך המחקר הרפואי, תוכנית המעקב הקליני: Worldwide there is an increasing prevalence of diabetes amongst many traditional communities and indigenous populations who are experiencing rapid changes in their lifestyle. They are becoming increasingly urbanised and ‘westernised’. They have a wider variety of foods and easier access to it, which causes a high intake of calories resulting in overweight when it is combined with less physical activity. The ongoing changes of Bedouin lifestyle as they settle in towns, influences their health. Bedouin food today contains a large amount of fat and carbohydrates. Physical activities have been reduced because they are no longer semi nomadic, herding their flocks and practicing agriculture. Both these factors have contributed to an increase in diabetes as a result of obesity and resistance to insulin in the muscles of the body. This affects the health of this population group and makes them more exposed to several diseases. The research will identify the lay beliefs, understandings and practice of Bedouin with diabetes and their families regard management of diabetes. It will also explore the views and practice of health professionals giving care to Bedouin with diabetes. Location of research: Primary Care clinic in Aroer and the Diabetic Clinic in Soroka Hospital. Inclusion criteria: Any Bedouin patients with type 2 diabetes over the age 18. Excluded criteria: Pregnant women, Type 1 diabetes, under aged 18 Time of research: 6 months (January 2007-July 2007)	

³³ קשר של העסקה בשכר, או קשר מסחרי או עסקי, או קשר משפחתי או אישי, וכל קשר אחר, לרבות קשר של כפיפות בעבודה, שיש בו כדי לעורר חשש לקיום ניגוד עניינים או תלות, ולמעט החרד הוצאות או תשלום עבור השתתפות בוועדות לפי נוהל זה.

החוקר מבקש פטור מהחמת המשתתפים על טופס הסכמה מדעת: כן לא		אם כן, נמק:
במקרה של ניסוי רב-מרכזי בישראל:		
רשימת המרכזים:		מס' המרכזים: _____ מס' המשתתפים: _____
שם המוסד הרפואי:	שם החוקר הראשי:	
1.	1.	
2.	2.	
3.	3.	
...	...	

הצהרת הרופא האחראי למחקר – החוקר הראשי

אני החתום מטה מתחייב לערוך את המחקר הרפואי בהתאם לעקרונות האתיים של הצהרת הלסינקי, תקנות בריאות העם (ניסויים רפואיים בבני-אדם) תשמ"א 1980, הנוהל לניסויים רפואיים בבני-אדם בישראל (2005) והנהלים הבינלאומיים העדכניים.

אני הח"מ מתחייב לערוך את המחקר בהתאם לפרוטוקול המצ"ב ולפי התנאים שייקבעו באישור למחקר הרפואי, לרבות הדיווח על אירועים חריגים במהלך הניסוי.

אני מצהיר בזאת, כי שקלתי את הסיכונים הטמונים ואי-הנוחות הצפויה כנגד התועלת הצפויה לחולה ו/או לחברה במחקר רפואי זה. לקחתי בחשבון, כי הזכויות, הבטיחות וטובתו של המשתתף במחקר יעמדו בפני כשיקולים החשובים ביותר, ויעלו בחשיבותם על כל תועלת למדע או לחברה.

אני מתחייב להסביר למשתתף/ת את מהות המחקר ולוודא שהבין/נה את ההסבר, ולקבל מראש את הסכמתו/ה בכתב של המשתתף/ת.

אני מצהיר, כי לא יימנע טיפול נאות מכל אדם שבחר לא להשתתף במחקר הרפואי, או שהחליט להפסיק את השתתפותו במחקר הרפואי.

אני מצהיר בזה, כי יש/אין¹ לי זיקה ליוזם המחקר הרפואי.

אני מתחייב בדבר שמירת הסודיות של המידע המזהה את המשתתף במחקר. מידע זה יהיה נגיש לאנשים המוסמכים לכך בלבד.

אני מאשר, כי אני מודע לעובדה שמתן האישור לעריכת המחקר הרפואי אינו משחרר אותי מהאחריות הרפואית המקובלת.

¹ מחק את המיותר; אם החוקר הראשי הוא גם יוזם המחקר, יש לציין זאת במפורש.

תאריך	מספר הרישיון	חתימתו	שם החוקר הראשי
	14374		ד"ר אילנה הרמן-בהם

מספר הבקשה בוועדת הלסינקי (למילוי על-ידי מזכירות הוועדה):
נושא המחקר הרפואי:
Indigenous people in context of modernity: the management of diabetes amongst Bedouin in Israel

א. חתימות החוקרים הנוטלים חלק בניסוי הרפואי:

תאריך	חתימתו	שם הרופא האחראי למחקר
		Dr Ilana Harman Boehm

תאריך	חתימתו	שם רופא/חוקר אחר הנוטל חלק במחקר (חוקרי משנה)
		Alshamari Abu-Nadi Ferial Alanood

ב. חתימת יו"ר החטיבה (בו יתבצע המחקר הרפואי):

תאריך	חתימתו	שם יו"ר החטיבה

ג. חתימת יו"ר החטיבה אחר אשר החולים המשתתפים המחקר מאושפזים/מטופלים במחלקתו):

תאריך	חתימתו	שם יו"ר החטיבה
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מספר הבקשה בוועדת הלסינקי (למילוי על-ידי מזכירות הוועדה): _____

אני החתום מטה:

שם פרטי ומשפחה:	
מספר תעודת זהות:	
מיקוד:	כתובת:

מצהיר/ה בזה כי אני מסכים/ה להשתתף במחקר רפואי^{4[4]}, כמפורט במסמך זה.

מצהיר/ה בזה, כי אני משתתף/לא משתתף^{5[5]} בזמן חתימת מסמך זה, בניסוי רפואי אחר במשך כל תקופת מחקר זה.

מצהיר/ה בזה כי הוסבר לי על-ידי:

שם החוקר/חוקר המשנה המסביר: Alshamari Abu-Nadi Ferial Alanood

כי החוקר הראשי: _____ Dr Ilana Harman Boehm קיבל ממנהל המוסד הרפואי, בו ייערך הניסוי, אישור לביצוע המחקר הרפואי בבני-אדם, כמשמעותו בתקנות בריאות העם (ניסויים רפואיים בבני-אדם) תשמ"א-1980 (להלן הניסוי הרפואי).

כי לחוקר הראשי ולחוקרי המשנה אין¹ זיקה ליוזם המחקר^{6[6]}.

אם יש – פרט:

כי המחקר הרפואי נערך בנושא:

Indigenous people in context of modernity: the management of diabetes amongst Bedouin in

Israel

^{4[4]} מחקר רפואי, כולל: לקיחת דמים, שאלונים, מחקר אפידמיולוגי, מחקר בדגימות רקמה וכו', פרט למחקר גנטי.

^{5[5]} מחק את המיותר

^{6[6]} אם החוקר הראשי הוא גם יוזם המחקר, יש לציין זאת במפורש.

כי אני חופשי/ה לבחור שלא להשתתף במחקר הרפואי, וכי אני חופשי/ה להפסיק בכל עת את השתתפותי במחקר, כל זאת מבלי לפגוע בזכותי לקבל את הטיפול המקובל.

כי במקרה של מילוי שאלון – אני רשאי/ת שלא לענות על כל השאלות שבשאלון או על חלק מהן.

כי מובטח לי שזהותי האישית תשמר סודית על-ידי כל העוסקים והמעורבים במחקר ולא תפורסם בכל פרסום, כולל בפרסומים מדעיים.

כי היוזם/ המוסד הרפואי (מחק את המיותר) פעל להסדרת כיסוי ביטוחי הולם של החוקרים, הרופאים והצוות הרפואי העוסקים בניסוי הקליני מפני תביעות שיוגשו ע"י משתתפים בניסוי הקליני ו/או תביעות צד ג' הקשורות עם הניסוי הקליני בין בתקופת ביצוע הניסוי ובין לאחריו. אין באמור כדי לפגוע בזכויותי על פי כל דין.

כי מובטחת לי נכונות לענות לשאלות שיועלו על-ידי וכן האפשרות להיוועץ בגורם נוסף (לדוגמא רופא-משפחה, בני משפחה וכו'), באשר לקבלת החלטה להשתתף בניסוי הרפואי ו/או להמשיך בו.

כי בכל בעיה הקשורה לניסוי הרפואי אוכל לפנות לפרופ' ד"ר אילנה הרמן-בהם,

מספר טלפון/משיכון: 08-6400583, פריאל אבו-ננדי טלפון: 0523924382, בכל שעות היממה.

הנני מצהיר/ה כי נמסר/ה לי מידע מפורט על המחקר הרפואי, על פי הנושאים המפורטים להלן: (נא לתאר פאופן מפורט לפי ראשי הפרקים הבאים)

מטרות המחקר; להבין את הבעיות באיזון סוכרת בקרב חולים מהמגזר הבדואי. לאתר את המעכבים והמעודדים לטיפול עצמי נכון של הסוכרת. לאתר משאבים בקהילה לשיפור הטיפול בסוכרת במגזר.

התקופה הצפויה למשך ההשתתפות במחקר והמספר בקירוב של המשתתפים במחקר; ראיון חד פעמי של כשעה. במקרים מסויימים גם ביקור בית.

תיאור ההליכים השונים במשך תקופת המחקר, תוך הבחנה ברורה בין ההליכים המחקריים לבין ההליכים המקובלים ברפואה; במרפאת קופת חולים המקומית יתבצע ראיון אישי של כשעה על ידי האחיות פריאל אבו-ננדי. חלק מהמראיינים יתבקשו לאפשר ביקור בית. במידה ותנתן הסכמה, הראיון יוקלט.

היתרונות הצפויים למשתתף או לאחרים, כתוצאה מהמחקר; הבנת הבעיות באיזון הסוכרת, איתור מעכבים ומעודדים של האיזון ואיתור משאבים לשיפור האיזון בקהילה צפויים לשפר את הטיפול בסוכרת בקרב חוזים מהמגזר הבדואי.

הסיכונים הידועים ו/או אי-הנוחות שניתן לחזותם למשתתף במחקר; השקעה של שעה אחת של זמן.

מידע רלוונטי אחר: כל הנתונים יאספו וישמרו ללא זיהוי של פרטי המראיין.

הנני מצהיר/ה בזה, כי את הסכמתי הנ"ל נתתי מרצוני החופשי וכי הבנתי את כל האמור לעיל. כמו-כן, קיבלתי עותק של טופס הסכמה מדעת זה, נושא תאריך וחתום כדין.

עם חתימתי על טופס הסכמה זה, הנני מתיר ליוזם המחקר הרפואי, לוועדת הלסינקי המוסדית, לגוף המבקר במוסד הרפואי ולמשרד הבריאות גישה ישירה לתיקי הרפואי, לשם אימות שיטות המחקר הרפואי והנתונים הקליניים. גישה זו למידע הרפואי שלי תבוצע תוך שמירת סודיות, בהתאם לחוקים ולנהלים של שמירת סודיות.

תאריך	חתימת המשתתף/ת במחקר	שם המשתתף/ת במחקר הרפואי

תאריך	חתימת העד	מספר תעודת זהות	שם העד הבלתי תלוי

הצהרת החוקר/חוקר המשנה:

ההסכמה הנ"ל נתקבלה על-ידי, וזאת לאחר שהסברתי למשתתף/ת בניסוי הרפואי כל האמור לעיל וכן וידאתי שכל הסבריי הובנו על-ידו/ידיה.

תאריך	חתימתו	שם החוקר/חוקר המשנה המסביר

כל טיפול, ניסויי ואחר, בקטין, חייב להיות ברוח סעיף 17 לחוק הכשרות המשפטית והאפוסטרופסות, תשכ"ב-1962 (קנה מידה לחובת ההורים):

17. "באפוסטרופסותם לקטין חייבים ההורים לנהוג לטובת הקטין כדרך שהורים מסורים היו נוהגים בנסיבות העניין".

על החוקר הראשי לניסוי הרפואי, מוטלת החובה להביא בפני ההורים את תוכן הסעיף האמור וכן, להסביר להורים את מהות הטיפול וטיבו, כולל התועלת הצפויה, הסיכונים הטמונים ואי-הנוחות העלולים להיגרם לקטין, ולוודא שההורים הבינו את כל המשמעויות הנ"ל.

לאחר שההורים הבינו, כאמור, יש להחתים את שניהם על טופס ההסכמה.

במקרים הבאים ניתן להסתפק בחתימת אחד ההורים:

על פי החלטת ועדת הלסינקי

משותפים ממשפחות חד-הוריות

כאשר ההורים גרושים, החוקר הראשי יחליט בכל מקרה באופן פרטני, בהתאם למידע המתקבל מההורים ויתעד את החלטתו על טופס ההסכמה החתום.

יש לקבל את הסכמת הקטין וחתימתו, במידה שהקטין מסוגל להבין את ההסבר.

במקרים המתאימים, (כגון במקרה של פסול-דין) יש לנהוג כך לגבי האפוסטרופוסים שהתמנו על-פי צו בית-משפט.

במקרים מיוחדים בהם הטיפול אינו סובל דיחוי ולא ניתן להשיג הסכמה משני ההורים, ניתן להסתפק בחתימת אחד ההורים, זאת, בהתאם לסעיף 18 לחוק הכשרות המשפטית והאפוסטרופסות תשכ"ב-1962. סעיף זה מותנה בקבלת אישור מראש בכתב של יו"ר ועדת הלסינקי של המוסד הרפואי, באשר להסכמתו כי לניסוי הרפואי האמור, ניתן להסתפק בחתימת אחד ההורים בלבד. כאשר חותמים שני

⁷¹⁷ במקרה שהמשתתף בניסוי, או נציגו החוקי, אינו מסוגל לקרוא את טופס ההסכמה מדעת, עד בלתי תלוי חייב להיות נוכח במשך ההסבר על מהות הניסוי הרפואי. לאחר שהמשתתף או נציגו החוקי הביע את הסכמתו בעל-פה להשתתפות בניסוי, העד יחתום על טופס ההסכמה, תוך ציון תאריך החתימה.

ההורים יש למחוק את סעיף (ה) בטופס 3, ואילו כאשר רק אחד מן ההורים חותם על טופס ההסכמה מדעת – יש למחוק את סעיף (ו) בטופס זה

מספר הבקשה בוועדת הלסינקי (למילוי על-ידי מזכירות הוועדה): _____

אנו החתומים מטה:

ההורים/האפוטרופוס של הקטין/החסוי/פסול דין⁸¹⁸ (להלן המטופל):

9[9]

שם האם:	מספר תעודת זהות:
שם האב:	מספר תעודת זהות:
שם האפוטרופוס:	מספר תעודת זהות:

שם המטופל	מספר תעודת זהות	תאריך לידה (אם המטופל מתחת לגיל 18 שנים)	כתובת

(א) מצהירים בזה, כי אנו מסכימים שהמטופל ישתתף במחקר רפואי, כמפורט במסמך זה.

(ב) מצהירים בזה, כי המטופל משתתף/אינו משתתף¹ בזמן חתימת מסמך זה בניסוי רפואי אחר במשך כל תקופת מחקר זה.

(ג) מצהירים בזה, כי הוסבר לנו על-ידי:

שם החוקר/חוקר המשנה המסביר:

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⁸¹⁸ מחק את המיותר

⁹¹⁹ מחקר רפואי, כולל: לקיחת דמים, שאלונים, מחקר אפידימיולוגי, מחקר בדגימות רקמה וכו', פרט למחקר גנטי.

1. כי החוקר הראשי (שם הרופא): _____ קיבל ממנהל המוסד ממנהל המוסד הרפואי אישור לביצוע המחקר הרפואי בבני-אדם, כמשמעותו בתקנות בריאות העם (ניסויים רפואיים בבני-אדם) התשמ"א-1980 (להלן הניסוי הרפואי).
2. כי לחוקר הראשי ולחוקרי המשנה יש/אין¹ זיקה^{10[10]} ליוזם המחקר^{11[11]}.
אם יש – פרט: _____
3. כי המחקר הרפואי נערך בנושא: _____
4. כי אנו חופשיים לבחור שהמטופל לא ישתתף בניסוי הרפואי, וכי אנו חופשיים להפסיק בכל עת השתתפות המטופל בניסוי, כל זאת, מבלי לפגוע בזכות המטופל לקבל את הטיפול המקובל.
5. כי במקרה של מילוי שאלון – אני רשאי/ת שלא לענות על כל השאלות שבשאלון או על חלק מהן.
6. כי מובטחת לנו סודיות באשר לזהות האישית של המטופל ולזהות ההורים/האפוטרופוסים^{12[12]}. סודיות זו תישמר על-ידי כל העוסקים והמעורבים במחקר ולא תפורסם בכל פרסום כולל בפרסומים מדעיים.
7. כי היוזם/ המוסד הרפואי (מחק את המיותר) פעל להסדרת כיסוי ביטוחי הולם של החוקרים, הרופאים והצוות הרפואי העוסקים בניסוי הקליני מפני תביעות שיוגשו ע"י משתתפים בניסוי הקליני ו/או תביעות צד ג' הקשורות עם הניסוי הקליני בין בתקופת ביצוע הניסוי ובין לאחריה.
אין באמור כדי לפגוע בזכויותינו על פי כל דין.
8. כי מובטחת לנו נכונות לענות לשאלות שיועלו על-ידינו וכן האפשרות להיוועץ בגורם נוסף (לדוגמא רופא-משפחה, בני משפחה וכו'), באשר לקבלת החלטה להשתתף בניסוי הרפואי ו/או להמשיך בו.
9. כי בכל בעיה הקשורה לניסוי הרפואי נוכל לפנות לפרופ'/ד"ר _____ מספר טלפון/משיבון: _____, בכל שעות היממה.
- ד. הנני מצהיר/ה כי נמסר לנו מידע מפורט על המחקר הרפואי, על פי הנושאים הכתובים להלן: (נא לאר באופן מפורט לפי ראשי הפרקים הבאים)
מטרות המחקר;
התקופה הצפויה למשך ההשתתפות במחקר והמספר בקירוב של המשתתפים במחקר;
תיאור ההליכים השונים במשך תקופת המחקר, תוך הבחנה ברורה בין ההליכים המחקריים לבין ההליכים המקובלים ברפואה;
היתרונות הצפויים למשתתף או לאחרים, כתוצאה מהמחקר;
הסיכונים הידועים ו/או אי-הנוחות שניתן לחזותם למשתתף במחקר;
מידע רלוונטי אחר:

^{10[10]} זיקה - קשר של העסקה בשכר, בקבלנות או בכל דרך אחרת, או קשר מסחרי או עסקי, או קשר משפחתי או אישי, וכל קשר אחר שיש בו כדי לעורר חשש לקיום ניגוד עניינים או תלות, ולמעט החזר הוצאות או תשלום עבור השתתפות בוועדות לפי נוהל זה.

^{11[11]} אם החוקר הראשי הוא גם יוזם המחקר, יש לציין זאת במפורש

^{12[12]} מחק את המיותר

(ה) הנני מצהיר/ה בזה^{13[13]} כי את הסכמתי הנ"ל נתתי מרצוני החופשי וכי הבינתי את כל האמור לעיל. כמו כן, הנני מתחייב/ת בזה לידע גם את אב/אם¹ הילד/הילדה¹ על הסכמתי להשתתפות בני/בתי¹ במחקר הרפואי. אם אב/אם¹ הילד/הילדה¹ אינו/אינה מסכים/ה לצרף את הסכמתו/ה להסכמתי, אני מתחייב/ת לידע על כך את הרופא האחראי וכן לבטל את הסכמתי להשתתפות בני/בתי במחקר הרפואי. כמו-כן, קבלתי לידי עותק של טופס הסכמה מדעת זה, נושא תאריך וחתום כדין.

(ו) הננו מצהירים בזה^{14[14]}, כי את הסכמתנו הנ"ל נתנו מרצוננו החופשי וכי הבננו את כל האמור לעיל. כמו-כן, קיבלנו עותק של טופס הסכמה מדעת זה נושא תאריך וחתום כדין.

(ז) עם חתימתי/חתימתנו¹ על טופס הסכמה זה, הנני/ו מתיר/ים ליוזם במחקר הרפואי, לוועדת הלסינקי המוסדית, לגוף המבקר במוסד הרפואי ולמשרד הבריאות גישה ישירה לתיק הרפואי של המטופל, לשם אימות שיטות המחקר הרפואי והנתונים הקליניים. גישה זו למידע הרפואי של המטופל תבוצע תוך שמירת סודיות, בהתאם לחוקים ולנהלים של שמירת סודיות.

תאריך	חתימת האב	תאריך	חתימת האם

תאריך	חתימת המטופל	תאריך	חתימת האפוטרופוס

במקרה הצורך^{15[15]}:

תאריך	חתימת העד	מספר תעודת זהות	שם העד הבלתי תלוי

הצהרת החוקר/חוקר המשנה:

ההסכמה הנ"ל נתקבלה על-ידי, וזאת, לאחר שהסברתי להורים/לאפוטרופוסים^{16[16]} של המשתתף/ת במחקר הרפואי כל האמור לעיל וכן וידאתי שכל הסבריי הובנו על-ידם.

תאריך	חתימתו	שם החוקר/חוקר המשנה המסביר

^{13[13]} במקרים בהם הורה אחד חותם על טופס ההסכמה ובתנאי שוועדת הלסינקי נתנה אישורה לכך.
^{14[14]} במקרים בהם חותמים שני ההורים או האפוטרופוסים/מיופי כח של המטופל
^{15[15]} במקרה שהמשתתף בניסוי או נציגו החוקי אינו מסוגל לקרוא את טופס ההסכמה מדעת, עד בלתי תלוי חייב להיות נוכח במשך ההסבר על מהות הניסוי הרפואי. לאחר שהמשתתף או נציגו החוקי הביע את הסכמתו בעל-פה להשתתפות בניסוי, העד יחתום על טופס ההסכמה תוך ציון תאריך החתימה.
^{16[16]} מחק את המיותר

נושא המחקר הרפואי: Indigenous people in context of modernity: management of diabetes amongst Bedouin in Israel	
שם ומספר הפרוטוקול:	
שם המחלקה:	שם החוקר הראשי: Dr Ilana Harman Boehm
שם המוסד הרפואי:	
שם היוזם וכתובתו:	
שם נציגו בארץ וכתובתו:	

17[17]

(1) היוזם מתחייב לפעול לפי הנהלים המקומיים והבינלאומיים לניסויים רפואיים, ובפרט בנושאים הבאים:

מסירת מידע אודות המחקר

הודעה למשרד הבריאות על מחקר רב-מרכזי בארץ

ניטור מהלך המחקר

דיווחי בטיחות

שמירת מסמכים

(2) היוזם מתחייב, כי אם יחליט לפרסם את תוצאות המחקר הרפואי בספרות מדעית, הוא יפרסמן במלואן ובלא להוציא דברים מהקשרם.

(3) ביטוח^[18]:

3.1 בניסוי שבו היוזם הוא חברה מסחרית: היוזם מתחייב לבטח את האחריות החוקית שלו על פי דיני מדינת ישראל מפני תביעות שיוגשו על ידי משתתפים בניסוי הרפואי ו/או תביעות צד ג' – הכל בהקשר עם הניסוי הרפואי, בין בתקופת ביצוע הניסוי הרפואי ובין לאחריו. הביטוח יורחב לכלול את האחריות החוקית של המוסד הרפואי ו/או הצוות הרפואי ו/או החוקר (להלן- "עורכי הניסוי") הנובעים

^{17[17]} חובת עריכת ביטוח קיימת רק במחקרים רפואיים בהם מבוצעת פרוצדורת רפואית כלשהי במשתתף.

^{18[18]} מחקר רפואי, כולל: לקיחת דמים, שאלונים, מחקר אפידמיולוגי, מחקר בדגימות רקמה וכו', פרט למחקר גנטי.

מהמעורבות שלהם בעריכת הניסוי, בכפוף לחריג של מעשה שנעשהברשלנות או חריגה מכוונת מפרוטוקול הניסוי.

3.2 בניסוי שבו היוזם הוא החוקר שאינו חברה מסחרית: חתימת מנהל המוסד הרפואי (או מי שהוסמך על-ידו) על מסמך זה מאשרת קיומו של ביטוח הולם של המוסד הרפואי לעורכי הניסוי.

3.3 היוזם יידע על כל תביעה או פוטנציאל לתביעה מיד לאחר שהדבר יובא לידיעת המוסד הרפואי או לחוקר.

3.4 החוקר, המוסד הרפואי ועובדיו יתנו ליוזם על פי בקשתו בכתב, תמיכה סבירה בכל מקרה של תביעה שתוגש נגדו, כאמור לעיל.

(4) טופס זה מהווה חלק בלתי נפרד מן ההסכם שבין החברה המממנת את הניסוי הרפואי ובין המוסד הרפואי.

היוזם:

תאריך	חתימה	ם
		מנהל המוסד הרפואי או מי שהוסמך על-ידו:
תאריך	חתימה	שם
		החוקר הראשי:
		Dr Ilana Harman Boehm
תאריך	חתימה	שם

א. זהות המסמכים

הנני מצהיר בזאת שהעברתי לחוקר/לוועדת הלסינקי המוסדית¹ בתאריך

בקשה למחקר רפואי בנושא: Indigenous people in context of modernity: the management of diabetes amongst Bedouin in Israel

שם מוצר המחקר:

מסמכי הבקשה כוללים:

פרוטוקול מספר: גרסה: תאריך:

כולל תיקון מספר: מתאריך:

ספרות רלוונטית

טופס הסכמה מדעת: גרסה: מתאריך:

מסמכים נוספים (אם יש):

ידוע לי כי האישורים לבקשה (טפסים 6 ו-7) יינתנו על-סמך המסמכים האלה.

¹ מחק את המיותר

ב. שינויים במסמכי הבקשה

אין

יש².

שם יוזם הניסוי או נציגו בארץ: תאריך:

חתימה: חותמת החברה (אם קיימת):

א. למילוי על-ידי החוקר הראשי:

טופס בקשה

טופס 1ה'

טופס הסכמה מדעת

טופס 2ג': גרסה: מתאריך:

טופס 3ג': גרסה: מתאריך:

טופס התחייבות היוזם

טופס 4ג'

טופס הצהרת היוזם – טופס 5

נוסח פרסום מודעה לגיוס משתתפים למחקר רפואי – טופס 10

פרוטוקול הניסוי הרפואי: מספר תאריך: גרסה:

בדקתי ווידאתי שכל המסמכים הדרושים לבקשה כמפורט בסעיף א' לעיל נמצאים:

שם החוקר הראשי	חתימה	תאריך

ב. למילוי על-ידי יו"ר/מזכירות ועדת הלסינקי:

בדקתי ווידאתי שכל המסמכים הדרושים לבקשה כמפורט בסעיף א' לעיל נמצאים:

שם יו"ר/מזכירת ועדת הלסינקי	חתימה	תאריך

² במידה שהוכנסו מראש שינויים במסמכים, כגון: השמטת סעיף ההתחייבות לאספקת מוצר המחקר לאחר סיום הניסוי הרפואי (בטפסים 2 ו-4), יש לצרף רשימה מפורטת לטופס זה. כמו כן, יש לפרט בטופס הבקשה, בסעיף "בקשות מיוחדות", באלה מסמכים הוכנסו השינויים.

א. למחקר רפואי הכולל טיפול או אבחון ניסיוני:

דרושים/ות מתנדבים/ות למחקר רפואי הכולל טיפול/אבחון ניסיוני ^[19]
במוסד רפואי: במחלקה:
מתקיים מחקר רפואי בתכשיר רפואי/אביזר רפואי/מכשיר רפואי ¹ חדש ^[20] בנושא:
המעוניינים/ות להשתתף מתבקשים/ות לפנות בטלפון:
בימים: בשעות:

ב. למחקר רפואי במתנדבים בריאים:

דרושים/ות מתנדבים/ות בריאים/ות למחקר רפואי:
במוסד רפואי: במחלקה:
מתקיים מחקר רפואי בנושא:
המעוניינים/ות להשתתף מתבקשים/ות לפנות בטלפון:
בימים: בשעות:
המשתתפים/ות יזכו בתמורה כספית.

נספח אבטחת מידע
אוניברסיטת בן-גוריון בנגב ומרכז רפואי סרוקה
טופס הצהרת אחראי לביצוע מחקר בעניין הגנת הפרטיות (חוק מהתשמ"א 1981)

הגדרות:

"מידע" - מידע או מידע רגיש ע"פ חוק הגנת הפרטיות התשמ"א 1981 .

"מידע" - נתונים על אישיותו של אדם, מעמדו האישי, צינעת אישיותו, מצב בריאותו, מצבו הכלכלי, הכשרתו המקצועית, דעותיו ואמונתו.

"מידע רגיש" - נתונים על אישיותו של אדם, צינעת אישיותו, מצב בריאותו, מצבו הכלכלי, דעותיו ואמונתו, וכן מידע ששר המשפטים קבע בצו שהוא מידע רגיש.

מחק את המיותר

[19]19

בניסוי בטכנולוגיות חדשות יש להוסיף מילה

[20]20

"פרטי מידע דמוגרפיים" - פרטים אישיים המאפשרים לזהות את האדם. לדוגמה: מספר תעודת זהות, מספר דרכון, שם, כתובת, טלפון, דואר אלקטרוני וכדומה.

"מספר נבדק" - מספר או מזהה אקראי המשמש כתחליף ל"פרטי מידע דמוגרפיים". תנאי הכרחי הוא שלא ניתן לזהות דרך "מספר נבדק" את האדם שפרטיו מופיעים במאגר.

"פרוייקט" - מחקר, ניסוי, עבודה וכדומה.

"פרוייקט מאובטח" - "פרוייקט" העושה שימוש ב"מידע", באמצעות מחשבים

"יחידת המחשוב" - יחידת המחשוב של הפקולטה למדעי הבריאות או של בית החולים סורוקה.

"קצין אבטחת מידע" - איש אבטחת מידע ב"יחידת המחשוב"

"חוק" - חוק הגנת הפרטיות 1981 - תיקון אחרון 13.8.00

ההצהרה

ידוע לי כי יש להמנע משמוש בפרטים המזהים את החולים במידה והפרטים אינם חיוניים למחקר/עבודה וכי מומלץ להשתמש במקום זאת במספר נבדק (מספר רץ נייטרלי שלא ניתן באמצעותו לזהות את האדם הנבדק).

מאגר המידע בפרוייקט מכיל: (הקף בעיגול את התשובה המתאימה)

א. "מידע רגיש" (כהגדרתו ב"חוק") כיוון שהוא מכיל את פרטי המידע הבאים:

ב. "מידע" (כהגדרתו ב"חוק") כיוון שהוא מכיל את פרטי המידע הבאים:

לא מכיל "מידע" או "מידע רגיש" כיוון שהמאגר משתמש במספר נבדק נייטרלי במקום בפרטים דמוגרפיים שניתן לזהות באמצעותם את האנשים.

לא מכיל כלל פרטי מידע המוגדרים "מידע" או "מידע רגיש", כהגדרתו ב"חוק".

המשך ההנחיות בהצהרה רלוונטי רק למי שסימנו תשובות 2א או 2ב. אם סימנתם תשובות 2ג או 2ד נא לעבור לחלק החתימה בסוף המסמך.

מיקום איסוף ועיבוד הנתונים

הנתונים נאספים ומעובדים במקומות הבאים: (ניתן לציין יותר ממקום אחד)

מרכז רפואי סורוקה

הפקולטה למדעי הבריאות

מרפאות קופת חולים - נא לפרט _____

מקום אחר - נא לפרט _____

שמירת המידע בשרתים

יש לשמור את המידע בשרת מאובטח ביחידת המחשוב במרכז רפואי סורוקה או ביחידת המחשוב בפקולטה למדעי הבריאות. השרות כולל אחסון וגיבוי הנתונים. המידע במחקר זה ישמר (הקף בעגול את התשובות הנכונות):

על שרת מחשב ביחידת המחשוב במרכז רפואי סורוקה

על שרת מחשב ביחידת המחשוב בפקולטה למדעי הבריאות

מקום אחר – נא לפרט:

ידוע לי כי המידע חייב להשמר אך ורק בשרתים המאובטחים של יחידת המחשוב.

ידוע לי שאמצעי אחסון הבאים לא מאובטחים ולא מתאימים לשמירת מידע רגיש:

מחשב אישי במשרד

מחשב אישי בבית

תקליטור

דיסקט

דיסק-מפתח disk-on-key

דואר אלקטרוני

וכדומה.

שימוש במחשב נייד

אם המחקר מחייב שימוש במחשב נייד – לדוגמא איסוף נתונים בשטח – יש לאבטח את הנתונים בעזרת אמצעים פיזיים ובעזרת הצפנה, עפ"י הנחיות יחידת המחשוב בבית החולים סורוקה.

האם המחקר דורש שימוש במחשב נייד?

במחקר לא משתמשים במחשב נייד

במחקר כן משתמשים במחשב נייד. השימוש הוא לצרכים הבאים:

ידוע לי כי שימוש במחשב נייד לצורכי ניסוי/מחקר זה דורש אשור מראש של קצין אבטחת המידע ביחידת המחשוב של ביה"ח סורוקה ובחתימה על הצהרת שימוש במחשב נייד. השימוש במחשב כרוך בתוספת תכנה וחמרה, והכנה. הנני מתחייב לכסות הוצאות התאמה כפי שנקבעים ע"י יחידת המחשוב.

האשור ינתן רק במידה והמחשב הנייד יעמוד בקריטריונים של אבטחת המידע כפי שיהיו מקובלים בעת הבקשה.

הגישה למידע דורש הזדהות (login וסיסמה). ידוע לי כי פרטי ההזדהות הינם אישיים. לא אשתמש בפרטי הזדהות שאינם שייכים לי ולא אתן לאף משתמש אחר את פרטי ההזדהות שלי. הנני מתחייב לשנות את הסיסמה שלי כל 6 חודשים ולהקפיד כי הסיסמה תכלול 8 תווים כאשר בתוכה לפחות תו אחד אותיות אנגליות קטנות, תו אחד אותיות אנגליות גדולות ותו אחד – ספרה.

הנני מתחייב לשמור את פרטי ההזדהות שלי חסויים.

הנני מתחייב להודיע מראש ל"יחידת המחשוב" על התחלת וסיום העבודה של כל אדם בצוות המחקר. לא יגש עובד חדש למידע השייך למחקר/ניסוי בטרם בדקתי ווידאתי כי העובד חתום על התחייבות לשמירת סודיות ואבטחת מידע, ונתנו לו פרטי הזדהות וקבל הרשאת גישה ממוחשבת למידע הרלוונטי ע"י "קצין אבטחת מידע".

אני מתחייב בדבר שמירת הסודיות של המידע המזוהה את המשתתף במחקר/ניסוי. המידע יהיה נגיש אך ורק לאנשים בצוות המחקר שנרשמו על ידי לפרוייקט אצל "קצין אבטחת המידע".

אני מתחייב לנהל את המחקר בהתאם בדרישות חוק הגנת הפרטיות התשמ"א 1981. (לעיון בחוק ראה: <http://medic.bgu.ac.il/comp/security/haganathapratiot.pdf>). כמו כן ארשם את המאגר אצל רשמת המאגרים אם זה נדרש.

העברת "מידע" לאנשים שאינם רשומים בצוות המחקר (אצל "קצין אבטחת המידע") תבוצע על פי הנוהלים בחוק הגנת הפרטיות התשמ"א 1981.

שם המחקר:

מחלקה

שם חוקר ראשי: _____ ת.ז. : _____
חתימת חוקר ראשי _____ תאריך הגשה : _____

לפרטים נוספים ויעוץ בעניין מאגרי המידע ניתן לפנות אל קצין אבטחת המידע ביחידת המחשוב במרכז רפואי סורוקה, טל. פנימי 3546 או לקצין אבטחת המידע ביחידה למחשוב רפואי בפקולטה למדעי הבריאות בטלפון פנימי 7471.

Appendix G: Research Authorization Form - Southern Region



טל': 6254202-08 פקס: 6254237-08

נוהל אישור מחקר – מחוז דרום

מחוז דרום מקדם ביצוע מחקרים רפואיים - העיסוק של הצוות במחקר מקדם את העשייה הרפואית, מגביר את המוטיבציה של הצוות, מפחית שחיקה ובסופו של דבר משפר את השירות הרפואי.

על מנת לוודא שכל המחקרים במחוז מבוצעים בצורה מסודרת וללא תקלות, יש לבצע מחקרים רק ורק לאחר קיום נוהל אישור מחקר. אין לבצע מחקרים במחוז ללא קבלת אישור בכתב למחקר.

ועדה של מחוז דרום נפגשת אחת לשבועיים לאישור מחקרים המבוצעים המחוז.

הפריטים הבאים נדרשים להגשה לועדה:

טופס אישור מחקר- מחוז דרום (נא להקפיד על מילוי תקציר בעברית)

פרוטוקול מחקר

אישור למחקר מועדת הלסינקי

אישור כיסוי ביטוחי (במידה ונדרש)

נא להגיש את כל המסמכים באמצעות ההנהלה הרפואית, מחוז דרום.

08-6292922 טלפון –

פקס – 6292923-08

rachelba@clalit.org.il מייל –

אישור לביצוע המחקר ישלח לחוקרים לאחר ישיבות הועדה.

בברכה,

ד"ר ארנון כהן

רכז מחקרים מחוזי

על בריאות כללית

טופס אישור מחקר- מחוז דרום

נא להקפיד על מילוי מדוייק. טופס ללא תקציר או ללא מילוי כל הסעיפים יוחזר לשולח

כותרת המחקר:

חוקר ראשי:

חוקרים נוספים:

תקציר המחקר (עד 150 מלים, בעברית)

ספירת מלים של התקציר: _____

רקע:

שאלת המחקר:

שיטות:

פרוטוקול מלא (בקובץ נפרד)

אישור ועדת הלסינקי (בקובץ נפרד)

אישור כיסוי ביטוחי (בקובץ נפרד, במידה ונדרש)

פרטי המחקר:

חוקר ראשי: _____

חוקר מהמחוז: _____ (תנאי הכרחי לקיום המחקר)

שמות כל החוקרים: _____

האם המחקר משותף לגורמים נוספים? _____

עלות אפשרית למחוז:

? האם יש צורך בתשומות כלשהן של המחוז

לא - כל התשומות (עבודה וחומרים) ע"ח החוקרים

כן, פרט: _____

עלות צפויה: _____

מקור המימון: _____

7. אישור הנהלה רפואית:

5.1 מאושר

מאושר בתנאים:

פירוט: _____

לא מאושר:

נימוק: _____

7. אישור אגף תכנון

7.1 יש צורך באישור מראש

7.2 הועבר לידיעה

8. הערות:

תנאים לאישור מחקר:

8.1 – חוקר ממחוז הדרום של שירותי בריאות כללית יהיה המחבר הראשון בכל הפירסומים הנגזרים מהמחקר (למעט מחקרים משותפים למספר רב של מרכזים רפואיים, בהם החוקר ממחוז דרום הינו אחד השותפים ואינו היוזם העיקרי של המחקר).

8.2 – העדר עלויות למחוז

8.3 – אישור וועדת הלסינקי

8.4 – עמידה בתנאי אגף תכנון

8.5 – במחקר קליני – אישור כיסוי ביטוחי.

משך זמן מחקר צפוי: _____

10. פרטי המאשר:

תאריך: _____

11. מעקב:

Appendix H: Information sheet for Bedouin patients with diabetes

Dear

My name is Ferial Abu Nadi. I am a nurse and have studied at Ben Gurion University for my B.Sc in Nursing and my MSC in Epidemiology. Now, I am PhD student at the University of Warwick and I am researching the topic of managing diabetes amongst Negev Bedouin. Diabetes is a health problem that affects many people in Bedouin society. I would like to know how Bedouin patients and their families manage to live with diabetes in their daily life, and what they are think about diabetes and the treatments for it. The aim of this study is to improve the care and experience of Bedouin living with diabetes. I will also be observing care and consultations in clinics.

I would like to interview 40 patients (men and women) with diabetes and give them the opportunity to talk about the disease. The interview will take about one hour and it will be in one of the rooms at the clinic. I would like to visit some of these patients at home and talk with them and their families about living with diabetes.

If you agree to take part in this research, by being interviewed, you have the right to stop the interview and withdraw from the research in any stage. Anonymity will be kept through the research. I will not publish any details that will expose who were the participants. Your name and family details will not be used so it will not be possible for anyone to know that you took part in this study.

Appendix I: Information sheet for Bedouin patients with diabetes (Arabic)

ورقة معلومات عن مرض السكري عند البدو

اسمي فريال ابو-نادي, درست تمريض والماجستير في جامعة بن-غريون في مدينة بئر السبع. الان, احضر رسالة الدكتوراه في بريطانيا حول موضوع السكري عند البدو. مرض السكري يصيب الكثير من أفراد المجتمع البدوي. في دراستي اود معرفة تجربة مريض السكري وعائلته, عن حياتهم اليومية مع المرض, ما هي افكارهم ومعتقداتهم عن السكري وعن علاجه. هدف الدراسة هو تحسين العناية بمريض السكري وتحسين تجربته مع المرض.

لمعرفة كل هذا اود اجراء مقابلات شخصيه مع حوالي 40 مريض سكري (رجال ونساء) الذين يتم اعطائهم فرصة التحدث عن تجربتهم مع المرض. كل مقابله تستغرق قرابة الساعه وستجرى في العياده. بعدها سوف اقوم بزيارة بعض المرضى في البيت والحديث مع افراد الاسره عن تجربتهم ومعايشتهم لمرض السكري. المشارك/ه في الدراسة له/ا الحق في انهاء المقابله في أي وقت والانسحاب من الدراسة. هذا الامر لن يأتري على حقه/ا في تلقي العلاج الطبي. السريه التامه سوف تحترم في خلال كل مراحل الدراسة. في حال نشر الدراسة لن تنشر أي تفاصيل عن أي مشارك/ه. اسم العائله والاسم الشخصي لن يظهر في أي اوراق وسوف تكون في تحفظ في سريه تامه.

اشكركم للمشاركة في هذا الاستطلاع.

Appendix J: Informed consent form for the Bedouin patients

I agree to take part in the research aiming to understand more about the management of diabetes by Negev Bedouin.

I have read and understood the information sheet. Yes/No

I agree to be interviewed by the researcher Yes/No

I agree that the interview may be audio-taped. Yes/No

I agree that the researcher can visit me at my home and interview myself and members of my household Yes/No

I understand that any information I provide is confidential and my identity will not be revealed.

I understand that my participation is voluntary and that I can stop the interview or withdraw at any stage of the research.

Name of the participant:

Signature:

Date:

Name of researcher:

Signature:

Date:

Appendix K: Informed consent form for the Bedouin patients (Arabic)

نموذج 2 ج – صفحة 1 من 2

نموذج موافقه على المشاركة في البحث الطبي

رقم الطلب في لجنة هليسينيكي (التعبئة تجرى على يد سكرتارية اللجنة): _____

أنا الموقع أدناه:

الاسم:
رقم الهوية:
الهاتف:
العنوان:

أقر بأنني موافق/ه على المشاركة في البحث المجرى عن مرض السكري.

أقر بأنني مشارك / غير مشارك في وقت توقيع هذه الاستمارة, في تجربته طبية أخرى في نفس الفترة.

أصرح بأنني تلقيت شرح من:

اسم الباحثة/ الباحث الثانوي : فريال ابو نادي

أن الباحثة الرئيسية الدكتورة ايلانه هارمن باهم أخذت موافقة من مدير المؤسسة الصحيه على إجراء هذا البحث.

بان الباحث الأولي والثانوي ليس لديهم أي علاقه بمن بادر بالبحث.

البحث الصحي هو بعنوان: السكان الأصليين والتطور الحضاري: إدارة مرض السكري عند البدو في إسرائيل.

أعلن باني مخير/ مخيره بمعدم المشاركة في البحث الصحي , وكذلك إني مخير/مخيره بالتوقف عن المشاركة في البحث في أي وقت أريد, مع العلم بان هذا الأمر لا يضر بحقي في تلقي العلاج الطبي.

في حالة إملاء استمارة للبحث يحق لي عدم الاجابه عن بعض الاسئلة.

الباحثين والعاملين في البحث أكدوا لي بان هويتي الشخصية ستحفظ بسريه, ولا تنشر في أي نشره حتى في نشرات علميه.

بان مبادر البحث/ المؤسسه الصحيه سيغطي التامين للباحثين, الاطباء, والطاقم الطبي العامل في هذا البحث من أي شكوى قضائية من قبل المشتركين في البحث في فتره البحث وما بعدها.

تأكد لي انه سوف يتم الاجابه على كل الاسئلة المطروحه مني ويحق لي كذلك استشارة أي طرف اخر (طبيب العائله, احد افراد العائله, وغيرها) , بشأن المشاركة او استمرار في البحث.

يحق لي التوجه للدكتوراه ايلانه هارمن باهن 086400583 او فريال ابو نادي 0523924382 بكل سؤال يواجهني عن البحث.

شرح لي عن البحث الصحي واهدافه كما هو مبين على النحو التالي:

اهداف البحث: فهم المشاكل المتعلقة في عدم الاتزان في مرض السكري عند البدو. الكشف عن الامور التي تاخر او تحسن علاج السكر. البحث عن موارد جماهيريه تحسن علاج السكري في الوسط البدوي.

الفترة الزمنية للمشاركة في البحث وعدد مرات اللقاء: مقابله واحده لمدة ساعة. في بعض الحالات سوف تجرى مقابله في البيت.

وصف عملية البحث: سوف تجرى مقابله في مبنى العياده المحليه لمدة ساعة من قبل الممرضه فريال ابو-نادي. بعض من المقابلات سوف تجرى في البيت, في حالة تمت الموافقه من قبل المريض.

الايجابيات المتوقعه للمشارك في البحث: فهم مشاكل السكري عند البدو, الكشف عن معوقات والامور التي تسهل المحافظه على مستوى السكر. ايجاد موارد جماهيريه لتحسين علاج السكر عند مرضى السكر البدو. سلبيات البحث: تقديم ساعه من وقته.

معلومات مهمه اخرى: كل المعلومات الطبيه التي يتم جمعها سوف تحفظ بدون اسم المرض.

هـ- اصرح بانني وافقت على المشاركة في البحث من محض ارادتي وبانني فهمت كل ما شرح لي من قبل. كما اني قد تلقيت نسخه من الموافقه بالتاريخ الذي تم.

و- بعد توقيعي على هذه الاستماره, يحق للمبادر بالبحث, لجنة هليسكي, الجسم المارقب في المؤسسه الصحيه وكذلك وزارة الصحه بالاطلاع على ملفي الصحي, من اجل استكمال طرق البحث الطبي والمعطيات الطبيه.

مع العلم بان كل هذا سوف يتم بسريه تامه, بما يتناسب مع القوانين للحفاظ على سرية المعلومات.

تاريخ	توقيع المشترك/ه في البحث	اسم المشترك/ه في البحث الطبي

وقت الضروره

تاريخ	توقيع الشاهد/ه	رقم الهويه	اسم الشاهد/ه غير المرتبط

تصريح الباحث الاولي/ الثانوي:

تمت الموافقة على البحث في حضوري, وهذا بعد ان شرحت للمشارك/ه في البحث الصحي عن البحث كما
شرح سابقا وتأكدت إن شرحي قد فهم من قبل المشارك/ه.

Appendix L: Semi-Structure Interviews Guidelines

Could you tell me about your experience with diabetes?

Feeling

Family

Tell me about the process you diagnosed with diabetes? (symptoms, feelings)

How he/she feel

Where did he/she go?

Tell me about your treatments and examinations for diabetes?

Type of treatment

Blood test (HBA1c, cholesterol, glucose), urine test

Eyes test

How diabetes does affect your daily life?

House work

Feeling (tired)

How diabetes does affect your social life?

Join neighbours in tea or coffee

Attend family weddings/events

What is your family think about diabetes?

Knowledge about diabetes

Feelings

How diabetes affected you mood?

Irritating

Feel sick

Upset

Changeable mood

What do you think the better way to treat diabetes?

Adhere to doctors recommendation

Folk medicine, Drink camel milk, Herbs (Helba)

Food, physical activity

What are you doing to keep your diabetes in balance?

Diet

Physical activity

Take medicine

What are you think the doctor/nurse role to keep your diabetes in balance?

Appointment

Food

Mood

Community programme run in your place are you going to join it, which kind of programme you would like to join?

Physical activity

Walking

Cooking

Support group

Appendix M: Semi-Structure Interviews Guidelines (Arabic)

تعليمات لأجراء مقابله مبنية جزئيا مع مرضى السكري عند البدو

حدثني عن تجربتك مع مرض السكري

مشاعر انتابتك

الأهل

حدثني كيف تم تشخيص السكر عندك (اعراض ومشاعر)

شعوره؟

اين ذهب؟

حدثني عن علاجك والفحوصات التي اشريتها لمرض السكري

نوع العلاج

فحوصات الدم

فحص العيون

كيف يؤثر السكري على حياتك اليوميه

الاعمال البيتيه/ الوظيفه

تعب

كيف يؤثر السكري على حياتك الاجتماعيه

الجلسه مع الجارات او مجلس الرجال لاحتساء الشاي والقهوه

المشاركه في مناسبات الاهل

ماذا ترى عائلتك مرض السكري

معرفةهم بالسكري

شعورهم

كيف يؤثر السكري على حالتك النفسية ومزاجك

عصبي

اشعر بالمرض طوال الوقت

قلق احباط

تقلب في المزاج

ماهي الطريقة المثلى لعلاج السكري

عمل ما يقول الطبيب

علاج الطبي الشعبي او النبوي

عن طريق التغذية والرياضه

ماذا تعمل للمحافظة على الاتزان في نسبة السكر

الحفاظ على حمية السكري

فعاليات جسميه

اخذ العلاج

ما هو دور الطبيب/الممرضه للحفاظ على توازن مرض السكري عندك؟

استدعائي للمقابلات عندهم

الحديث عن الاكل

دعمي معنويا

اذا كان هناك برنامج جماهيري للحد من السكر يجري في منطقتك فاي نوع من نوع من الفعاليات كنت ستشارك:

برنامج للحركه

برنامج للمشبي

برنامج عن الاكل الصحي

مجموعات دعم للسكري

Appendix N: Information sheet for health professionals

Dear

My name is Ferial Abu Nadi. I am a nurse and have studied at Ben Gurion University for my B.Sc in Nursing and my MSC in Epidemiology. Currently, I am PhD student at the University of Warwick and I am researching the topic of managing diabetes amongst Negev Bedouin. Diabetes is a health problem that affects many people in Bedouin society.

World-wide, Diabetes become a major health problem and the disease complication leading the in mortality rate. Transition from traditional lifestyle to sedentary due to urbanization process, is resulting in changes in dietary intake and lake of physical activity. According to many studies there are an association between these factors and diabetes.

The research will explore how Bedouin patients and their families manage to live with diabetes in their daily life, and what they think about diabetes and treatment. The aim of this study is to improve the care and experience of Bedouin living with diabetes. I will

I will also be observing care and consultations in clinics and interview diabetic patients and their family. I will conduct focus group with the health team working in Aroer clinic. It will take place during one of the team meeting.

If you agree to take part in this research, by being interviewed, you have the right to stop the interview and withdraw from the research in any stage. . Anonymity will be kept through the research. I will not publish any details that will expose who were the participants. Your name and family details will not be used so it will not be possible for anyone to know that you took part in this study.

Appendix O: Focus group topic guide for professionals

What is the diabetes management routine?

The General health service guidelines

Blood test and Examinations

What are doctor/ nurse roles in diabetes management?

Explain about diabetes

Send them to the test and examinations

Prescription treatment of diabetes

What do you think about diabetes situation amongst Bedouin?

Prevalence

Difficulties to bring them to control

Family connection

Tell me about your experience with diabetes management amongst Bedouin?

Control of diabetes

Adherence to health recommendation

What are the barriers preventing you when you deal with Bedouin patients' management of diabetes?

Time

Culture

Poor compliance

How do you think management can be improved amongst Bedouin diabetes patients?

Diet

Physical activity

How does diabetes affect Bedouin patients' daily life?

Their Feeling

Restriction in daily activity

Relation with family

Nutrition

Appendix P: Informed consent for health professionals

Iworking in..... agree to take part in this research study aiming to understand more about the management of diabetes by Bedouin. I have read and understood the aims of the research. I have had an explanation from the researcher and she has answered questions.

I agree to her observing clinic consultations with Bedouin patients

Yes/No

I agree to participate in a focus group or to be interviewed by the researcher.

Yes/No

I give my consent to allow her to audio-tape the interview.

Yes/No

I understand that any information I provide is confidential and my identity will not be revealed as all the data including the location of the clinic will be anonymised.

My participation is voluntary. I can withdraw from participating in the study at any stage.

Name of the doctor/nurse:

Signature:

Date:

Name of researcher:

Signature:

Date: