THE UNIVERSITY OF HULL

Support Needs for Diabetes Self-Management:
Exploring the Views of Maltese Individuals with Type 2
Diabetes using a Grounded Theory Approach

Being a thesis submitted for the Degree of Doctor of Philosophy

in the University of Hull

by

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July 2016

ABSTRACT

Diabetes is a long-term condition which causes significant public health concern in view of its increasing prevalence and associated morbidity. Notwithstanding this, effective management has been shown to prevent or delay the onset of diabetes complications, thereby improving prognosis. Diabetes has a high self-management demand. This involves behaviour modification together with psycho-social adjustments required to overcome challenges with integrating diabetes management in one's life. Such challenges often originate from the socio-cultural context and it is recognised that support for diabetes self-management should target these challenges. The purpose of this study was therefore to explore how Maltese individuals with Type 2 diabetes believe they can be supported to manage their condition, as well as to examine whether, and if so how such views may be shaped by the Maltese socio-cultural environment.

The study used a qualitative design guided by a Grounded Theory approach. Data were collected by in-depth focus group and one-to-one interviews, carried out amongst 52 adults with Type 2 diabetes recruited from an outpatient hospital clinic and community-based diabetes clinics in Malta. A total of six focus groups and twelve one-to-one interviews were conducted. Theoretical sampling was used and data analysis involved constant comparison of data, together with conceptualising and organising the data into categories. Generated categories were linked by exploring relationships between them, in the process of developing a substantive theory.

The emergent theory describes how participants viewed diabetes self-management as involving the implementation of skills in thought and behavioural management. These skills were found to be key to coping and consisted of flexibility, proactive management, stress management and developing a positive mind-set towards diabetes. Furthermore, the theory outlines how aspects of Maltese culture, including those related to stigma, family, food and health services were seen to influence diabetes self-management directly, or through their impact on the development of

such skills. A basic social process emerged representing individuals' movement across the coping continuum, characterising transition to a higher/lower level of coping, during particular episodes in life. This process reinforced the identified relationship between the socio-cultural context and patient's agency, demonstrating how such movement coincided with negative/positive experiences of socio-cultural influence.

These findings have contributed new knowledge about the relationship between culture and diabetes-related coping. They suggest that patients may be supported in managing their diabetes by addressing cultural factors which influence the development of specific self-management skills. In Malta, this may involve new ways of delivering culturally sensitive care and education.

ACKNOWLEDGEMENTS

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ACRONYMS

ADA	American Diabetes Association
BMI	Body Mass Index
CAQDAS	Computer assisted qualitative data analysis software
CCM	Chronic Care Model
CDC	Centre for Disease Control and Prevention
DAWN2	Diabetes, Attitudes, Wishes and Needs (second study)
DCCT	Diabetes Control and Complications Trial
DESMOND	Diabetes Education and Self-Management programme for Ongoing and Newly Diagnosed individuals
DSMS	Diabetes Self-Management Strategy
FG	Focus Group
GFL	Government Formulary List
GPs	General Practitioners
GT	Grounded Theory
HbA1c	Glycated Haemoglobin
HCP	Health Consumer Powerhouse
HiT	Health System in Transition series
ICT	Information Technology
ICIC	Improving Chronic Illness Care Team
IDF	International Diabetes Federation
Int	On-to-one Interview
LDL	Low Density Lipoprotein level
NCDs	Non-Communicable Diseases
NICE	National Institute for Health and Clinical Excellence
NSO	National Statistics Office
OHA	Oral Hypoglycaemic Agents
UKPDS	United Kingdom Prospective Diabetes Study
UN	United Nations
WHO	World Health Organisation

Chapter 1

INTRODUCTION

1.1   Introduction

This chapter introduces this study by presenting its purpose and highlighting its significance in healthcare. The chapter first describes the personal driving forces of this study with reference to my past professional and academic experiences. It then provides a succinct background to the study which emphasises its value as a subject for research. Lastly, the chapter describes the layout of the thesis by presenting a summary of each chapter.

1.2   Personal motivation to explore diabetes self-management support

I can trace my interest in diabetes from the beginning of my nursing career. I recall that amongst the patients whom I nursed, I was particularly struck by those admitted with diabetes complications, of whom there seemed to be so many. I still remember the devastating looks on patients' faces, as they learnt about their need for amputation, and some of these, were in my eyes, too young for such hardship. Neither can I forget the astounded look on doctors' faces as they identified signs of eye complications in their younger patients. We had always been taught that diabetes was a condition which could be managed and controlled and yet we were still faced with these situations. It is also hard to forget our frustrations when caring for these individuals, upon realising that despite our advice for dietary control, they would still hoard sweets in their bedside cupboards. Notwithstanding the complications they experienced, their 'unhelpful' behaviour would persist. Since those early days in my career, it became clear that these patients were desperately in need of support.

Back in 2003, I studied a specific aspect of diabetes self-management, namely insulin administration. This study examined the difficulties which Maltese individuals with Type 1 and Type 2 diabetes might have had to be independent in self-administrating their insulin (Buttigieg, 2003). Results of this quantitative research showed that the number of individuals who were dependent on others for their insulin administration was significant, marking 33% (95% CI 27, 39) of my 215 participants on insulin. This was despite the fact that only a small minority of these had physical problems which held them back from self-injecting. With such a high level of dependency on basic self-management skills, it did seem as though diabetes self-management in Malta could indeed be associated with particular challenges. In the meantime, quantitative studies began to produce evidence of poor diabetes control amongst Maltese individuals with this condition (Cutajar, 2008; Bugeja *et al.,* 2009; Grima, 2009). This evidence instigated further personal interest in getting to know what factors were influencing Maltese individuals' ability to self-manage their diabetes and what measures of support could address these factors.

No previous work on diabetes self-management support in Malta could be traced, so I chose to examine this area, using an exploratory approach to study patients' own views about this subject. I carried out in-depth interviews with individuals and groups of individuals with Type 2 diabetes, and explored their perspectives and experiences of living with diabetes within a Maltese culture. My methods, based on philosophical assumptions of the interpretive paradigm, and guided by the Grounded Theory Method, were targeted to answer the following research question:

What views do Maltese individuals with Type 2 diabetes have regarding their needs for diabetes self-management support?

1.3   Significance of the subject area

This study is about diabetes, a long-term condition which affects insulin production and / or insulin action, resulting in hyperglycaemia (American Diabetes Association, 2010). Diabetes is increasingly assuming a public health priority, not merely because of its steadily increasing prevalence, but also because of its high level of symptomatic burden. In fact, the International Diabetes Federation (IDF) declares

diabetes as one of the largest health emergencies of the 21st century (IDF, 2015). Diabetes is amongst the most prevalent long-term conditions (Islam & Azad, 2014) with the world average rate amongst adults estimated to be 8.8% (IDF, 2015). This rate is expected to rise substantially. In Malta, diabetes constitutes a significant health problem (Cuschieri & Mamo, 2014), marking an estimated prevalence rate of 13.9% amongst adults between 20 and 79 years of age (IDF, 2015).

Being established as a progressive disorder, diabetes is known to lead to disabling complications which could result in lower levels of productivity and poorer quality of life. Due to this, the condition exerts a substantial negative impact on both individuals and society (Rocchiccioli & O'Donoghue, 2004). Medical costs incurred by a person with diabetes have been calculated to be two to three times higher than those of a person without diabetes (IDF, 2015). The IDF (2015) calculates that about 11.6% of total health expenditure worldwide is spent on diabetes, amounting to approximately 1,622 to 2,886 US dollars on diabetes care per person with diabetes. This costing excludes indirect costs to society from lost productivity and other associated costs, and may thus be considered as a gross underestimation of the real cost of diabetes.

As in many other long-term conditions, diabetes management is hugely carried out by the individual him / herself, such that the focus is placed on promoting *self-management* of the condition. Diabetes self-management is, in itself, rather complex. It involves activity such as exercise, dietary control, self-testing and medication taking, aimed at maintaining a desirable level of blood glucose (Daly *et al.*, 2009; Khattab *et al.,* 2010). However, managing the physical impact of the condition is not enough. Authors have often highlighted that in the process of caring for one's chronic illness, the individual needs to deal with the psychological responses to having his / her condition and to cope with the social challenges involved with incorporating its management in everyday life (Richardson *et al.,* 2001; Barlow *et al.*, 2002; Greenhalgh, 2009).

Studies have often exposed the difficulties encountered by individuals when trying to meet the various demands of diabetes self-management, as mentioned above. For example, Vermiere *et al.* (2007) and Gomersall *et al.* (2011) who conducted a meta-

synthesis of qualitative studies about diabetes-related experiences, reported negative psychological responses to diabetes, such as feeling 'different' or experiencing feelings of 'failure' when blood glucose levels could not be regulated. These studies also identified various social challenges, such as those related to participating in social occasions involving food, or those arising within families, members of which rejected recommended food and cooking methods. Findings like these highlight the need to support individuals in their efforts to manage their condition.

As argued by Fisher *et al.* (2005), since much of one's diabetes experience is affected by circumstances within his / her social environment, self-management support needs to address the socio-cultural context, within which it takes place. Studies carried out amongst different cultures have identified common social sources of influence on self-management, such as those related to family and healthcare services (e.g. Furler *et al.,* 2008; Samuel-Hodge *et al.,* 2013). However, the manner in which these were found to impact on such management, varied across cultures. In light of this evidence, this study set out to explore views and experiences related to diabetes self-management in Malta, which could indeed be culture specific, determining distinct needs for support. The aim was to examine how the evidence would link with international literature about the cultural influence on diabetes self-management. It could also contribute to the available knowledge on diabetes self-management support and fill gaps in this literature. These gaps will be highlighted in the next chapter.

1.4   Thesis structure

This thesis consists of a total of ten chapters which present and discuss the context, methods and results of this study. While this chapter highlighted the significance of this study and outlined its purpose, the next chapter presents a literature background. It highlights important aspects of diabetes and its management and considers the research conducted to date on diabetes self-management support, identifying areas in this literature which are possibly under-developed. It also describes the Maltese context in which this study took place.

Addressing the methodology of this study, Chapter 3 discusses the philosophical principles that drove the selection of research methods. It first describes the epistemological foundations upon which the choice of the interpretive paradigm was made and explains how the nature of the research question led to choosing Grounded Theory (GT) as an approach to qualitative enquiry. It briefly discusses the theoretical underpinnings, central concepts and general features of GT, outlining their relevance and implications to this study.

Chapter 4 gives a detailed account of the research design and methods used for sampling, data collection, data analysis and theory construction. Advantages and limitations of methods used are discussed in light of related literature and factors within the Maltese context. Ethical considerations and issues related to rigour are also included. The chapter ends with a detailed account of the reflexive stance adopted in this study.

Chapters 5 to 8 present the main findings of this study and include discussions of these findings in relation to literature. Data analysis has produced four main categories and each of these chapters addresses one of these categories. Relationships between these categories are explored in Chapter 9 which presents and discusses the integration of the emergent substantive theory about diabetes self-management within the Maltese context. The theory is then compared to extant formal theories of social behaviour.

Chapter 10 concludes this thesis by first explaining how the emergent grounded theory contributed towards meeting the objectives of this study. It presents the strengths and limitations of this research study and outlines the implications drawn from the results. The chapter ends with a reflection on the personal development attained in the process of conducting this research.

Chapter 2

BACKGROUND TO THE STUDY

2.1   Introduction

This chapter provides a detailed background to this study with the aim of placing it 'in perspective.' It highlights the significance of diabetes and its management within the public health domain and gives an overview of the setting in which the study took place.

The first section of this chapter addresses the role of the literature review in this GT study and the methods employed for searching the literature. The chapter will then focus on long-terms conditions, highlighting their impact on public health. Literature which defines self-management of these conditions will be analysed. The chapter then focuses on diabetes as a long-term condition, looking at factors such as pathophysiology and epidemiology. It addresses the central role of self-management in delaying the onset of diabetes complications and describes the nature of such management. This is followed by an overview of research conducted to date on perceptions regarding self-management support, identifying limitations and gaps in this literature. Finally, the chapter describes the Maltese context where this study took place. The terms 'long-term condition', 'chronic illness' and 'non-communicable disease' will be used interchangeably in this thesis. These will refer to non-infectious conditions which are most often non-curable. They require management over a long period of time, involving co-ordinated interdisciplinary care, aimed at promoting patient empowerment.

2.2   Reviewing the literature

The GT method guided the approach to this study, including the manner by which

the literature was reviewed. As stated by Birks and Mills (2011) the use of literature in GT is one of the most contentious aspects of this research method. Charmaz (2006) suggests that in a GT study, the literature review provides an opportunity to compare existing evidence with one's grounded theory. In doing this, one may see how the theoretical concepts emerging from his/her study may extend or challenge prevailing ideas in one's field. That is, according to Charmaz (2006, p. 164), the literature review needs to be drafted "in relation to [one's] grounded theory" and *after* data analysis. In their original work, Glaser and Strauss (1967) had also suggested delaying the literature review until after the analysis. Their reason was to avoid importing preconceived ideas into data analysis. Much debate has evolved around this notion as the idea that the researcher can ever enter the research without predetermined ideas has been challenged (Strauss & Corbin, 1998). Notwithstanding the arguments in favour of delaying the literature review, it is generally acknowledged that to embark on a research project, one needs to read related literature in order to identify important gaps and to write research proposals. Charmaz (2006) suggests reading enough literature to meet these needs, but not developing this any further until after the analysis. In line with this argument, Urquhart (2013, p. 7) suggests that researchers should deeply engage with the literature after formulating their theory and use this to help them with the "densification" of their emergent theory.

In light of the arguments put forward above, it was decided that before my data analysis, I would read sufficient literature to confirm the importance of this area of study, to understand how this has been investigated, and to identify literature gaps which my study would address. This literature is presented in this chapter. Further reading was carried out after my analysis, and this was guided by my findings. This literature will be presented in Chapters 5 to 9 which address the categories developed from my data.

Whenever I was involved in searching for literature on a particular subject area, such as that related to a specific finding, a systematic search strategy was applied to retrieve relevant literature from among various electronic data bases. Details of this search strategy are given in Appendix 1. Relevant literature was also identified by going through reference lists of journal reports. The electronic base of the

University of Malta library was used to identify dissertations carried out locally about diabetes or related subjects. There was also relevant published and unpublished work that I read, which was brought to my attention outside of my systematic search strategy. This had been recommended to me by various experts in the related fields, whom I had contacted. Effort was placed to find and read seminal work in each of the areas reviewed.

2.3 Long-term conditions as a public health concern

According to the World Health Organisation (WHO) (2014), long-term conditions constitute one of the major health and economic challenges of the 21st century. Several factors are implicated in the increasing prevalence of these conditions, with a major underlying determinant being a longer lifespan. This is a result of gains in health obtained in the last few decades through improvements in public health services (Carrier, 2009). Other associated factors include decreasing physical activity, smoking, and increasing consumption of an unhealthy diet (Daar *et al.*, 2007). The consequences of long-term conditions for individuals, societies and economies are devastating, considering the human suffering they cause and their negative impact on the socio-economic development of countries (WHO, 2014).

Long-term conditions are the leading causes of death and disability across the globe. According to the WHO (2014), out of the 56 million deaths which occurred globally in 2012, 38 million (68%) were due to long-term conditions. These comprised mainly of deaths from the four major non-communicable diseases namely cardiovascular diseases, cancer, diabetes and chronic lung diseases. Economic implications of long-term conditions have also been reported. For example, it is estimated that each 10% rise in long-term conditions is associated with 0.5% lower rates of annual economic growth (Stuckler, 2008). The economic burden is brought about by an increase in health and social care expenditure and a reduction in economic productivity as a result of the inability to work. Although long-term conditions constitute a socio-economic issue which strikes both the rich and the poor, the consequences are greater for the poor in all countries (WHO, 2014). This continues to widen the socio-economic gap and health inequalities between members of the same population.

Besides exerting an economic toll, long-term conditions have other negative impacts on the individual. Carrier (2009) writes how a patient's life is often irreversibly changed with the onset of a long-term condition. Besides enduring the impact on physical health, the individual experiences psychological and social consequences, which affect every aspect of his/her life.

2.3.1   World Health Organisation's response to the problem

In response to the increasing prevalence of long-term conditions and the negative consequences of this trend, the WHO has long been urging action aimed at preventing and controlling these conditions. In the year 2000, the WHO endorsed the Global Strategy for the Prevention and Control of Non-communicable Diseases and developed an action plan in 2008 to help translate this strategy into concrete action (WHO, 2008). This plan covered the period between 2008 and 2013. In 2011, at the United Nations high-level meeting on Non-Communicable Diseases (NCDs), world leaders agreed on a set of concrete commitments to address the global impact of these conditions. This constituted the United Nations (UN) Political Declaration on NCDs (UN, 2012).

In order to accelerate national efforts towards addressing the problems associated with NCDs, in 2013, the World Health Assembly developed a world-wide monitoring framework and set nine voluntary global targets for 2025. These targets addressed the prevention of all the major modifiable risk factors, a reduction in the prevalence of hypertension, a halt in the rise of diabetes and obesity, improved accessibility to drug therapy and the availability of affordable technologies required to treat major NCDs. The overarching target was that of a 25% reduction of premature mortality from the four major NCDs by 2025. The Assembly also endorsed the WHO Global Action Plan for the Prevention and Control of NCDs covering the period 2013–2020 (WHO, 2013). This was organised around six objectives aimed at strengthening national capacities for the prevention and control of NCDs through better leadership, multi-sectorial action and international cooperation.

The WHO initiatives and reports mentioned above, focus on what could be done at

national levels to help individuals look after their health. The reports urge governments to do away with victim blaming, which view individuals as bringing the problems upon themselves through choosing unhealthy behaviours. Rather, governments should appreciate the influence of health damaging policies on individuals' choices. They should ensure that what people need in order to prevent or control long-term conditions is identified. These needs should be met through individual and population wide strategies, which empower people to make healthy choices. This is particularly important in the management of long-term conditions, where most of the care involved is dependent on everyday decisions and self-management actions made by the individual. This issue is dealt with in more detail in the section below.

2.3.2   Managing long-term conditions – focus on self-management

Disease self-management has a central role in the control of long-term conditions. Furthermore, focusing on a self-management approach has implications to the way that patients and patient care are perceived. This section discusses these issues and analyses the various approaches to defining self-management which have been identified in the literature.

A self-management approach to the management of long-term conditions, may contrast with that used in acute illness. In situations of acute illness, lay persons have been socialised to accept "the totality of medical authority" (Sarkadi, 2001, p.20). Here, it is believed that the illness is understood only by the professional who has to make all decisions regarding its cure. However, with long-term conditions, people are expected to carry out most of the management of their condition on their own, regardless of their age, educational level or economic status. As suggested by Bodenheimer *et al.* (2002), with long-term conditions, the question is not whether patients manage their illness, but how they do so. Each day, patients decide how they will control their symptoms, how they will manage their medications and how they will eat or exercise in relation to their condition. They are in control. Decisions are often influenced by a multitude of factors, which individuals come across while they try to integrate their condition with their everyday lives.

In light of this reality, it has long been suggested that patients are considered as 'experts' of their condition, and their direct involvement in care should be perceived as an important social resource (Levin, 1981). The implications of this conceptual view are various. Since patients are their own 'experts' in their experience of illness, but may lack medical knowledge, then care becomes based on a partnership between patients and healthcare providers and both care and education assume a collaborative approach (Bodenheimer *et al.,* 2002). Also, because self-management is seen as an indispensable healthcare resource, then efforts must be continually directed towards supporting it.

Definitions of self-management explicate the complex nature of activities involved with managing long-term conditions. These include managing symptoms, managing treatment and lifestyle changes, as well as monitoring one's condition (Bourbeau, 2003; Sturt *et al.* 2005; Kennedy *et al.*, 2007; Furler *et al.,* 2008). These activities may be geared towards building physiological reserves and preventing, detecting, as well as managing complications (Kennedy *et al.*, 2007). They constitute interconnecting elements which are central to self-management. This is characterised by the way activities affect one another, such that one activity (for example taking medication or exercising) would depend on the timing of another activity, such as eating. Therefore, carefully planning these activities becomes another important endeavour towards achieving illness control.

Greenhalgh (2009) points out that focusing only on activities to be performed means adopting a biomedical view of the self or of self-management. The individual's self-management ability becomes judged by his/her capacity or motivation to perform tasks assigned by health professionals. More than 60 years ago, the WHO has directed perceptions on health towards a more holistic view, emphasising the importance of physical, mental and social well-being when considering health issues (WHO, 1948). In fact, quality of life, which incorporates all dimensions of health, is widely recognised as an important health outcome in its own right (Fayers & Machin, 2007). Quality of life measures have often been found to be unrelated to physical well-being. For example, studies have repeatedly found low correlations between diabetes control and subjective well-being (Weinberger *et al.,* 1994; De Sonnaville *et al.,* 1998; Zhang *et al.*, 2011; Daher *et al.*, 2015).

In light of the above, Greenhalgh (2009) suggests framing a definition of self-management around a sociological self and focusing on coping with illness rather than simply 'managing' it. Similarly, assuming a holistic view of the individual, Richardson *et al.* (2001) write how self-management should start by understanding and eventually accepting the impact that the disease may have on the individual. Besides the physical impact, psychological and emotional responses to having a long-term condition are common. These may include feelings of anger, fear or frustration. Corbin and Struss (1988) write how self-management involves learning how to cope with these responses. In terms of managing the social impact of an illness, Bourbeau (2003) points to the need of developing an ability to maintain important social roles and relationships whilst caring for one's illness.

In the process of coping with all these demands, individuals with chronic illness have been reported to perceive the overall need of bringing back order in one's life, which could be compromised with the 'work' and limitations involved with having a chronic illness (Kralik *et al.*, 2004). This would involve not only practical measures, such as mobilising one's resources, but also the need of managing the shift in self-identity. This involves developing and accepting an altered perception of self which allows the illness to become part of life. These issues, depicting self-management as centred around the management of physical and psychosocial consequences of chronic illness, will be discussed in more depth in the next chapters.

2.4   About diabetes

2.4.1   Pathophysiology and resulting complications

The term 'diabetes' is given to a group of metabolic disorders which are characterised by hyperglycaemia resulting from problems with insulin production, insulin action, or both (American Diabetes Association (ADA), 2010). The body becomes unable to metabolise the three energy substrates, namely carbohydrates, protein and fat (Bilous & Donnelly, 2010). Diabetes is a progressive condition and it eventually leads to long-term damage, as well as failure of various organs (*ibid*.).

According to the ADA (2010), most of diabetes cases fall into one of two broad

categories. Type 1 diabetes is characterised by beta cell destruction which usually results in absolute deficiency of insulin. It is either idiopathic or immune mediated. Type 2 diabetes presents as a spectrum of metabolic abnormalities characterised predominantly by insulin resistance and relative insulin deficiency. It often results from excess body weight and lack of exercise (Bilous & Donnelly, 2010). There is also a genetic predisposition to developing Type 2 diabetes (*ibid.*). Type 2 diabetes, which makes up about 85% to 95% of all diabetes (IDF, 2011), is often asymptomatic in its early stages and can remain undiagnosed for many years (ADA, 2010).

Long-term consequences of diabetes include macrovascular and microvascular complications. The former are characterised by disease of the large and medium sized blood vessels, resulting in cerebrovascular, cardiovascular and peripheral vascular disease, while the latter arise from the thickening of vessel membranes in the capillaries and arterioles in response to chronic hyperglycaemia (Lewis *et al.,* 2010). Microvascular complications are specific to diabetes, that is, they do not occur in people with normal levels of blood glucose (Bilous & Donnelly, 2010). Microvascular complications result in diabetic retinopathy, nephropathy and neuropathy (Lewis *et al.,* 2010).

Since Type 2 diabetes in particular, occurs later in life, it is sometimes difficult to establish the extent by which symptoms related to diabetes complications result from diabetes or from the ageing process itself. However, as Clark and Asimakopoulou (2005) point out, while the development of various conditions, such as deteriorated vision and poor peripheral circulation, increase with age in the absence of diabetes, their incidence are all exaggerated by the presence of diabetes. For example, rates of myocardial infarction and stroke are increased approximately two-fold, the risk of visual loss is increased by approximately 40 per cent and the risk for lower extremity amputation is approximately 10-fold greater in the person with diabetes (Clark & Asimakopoulou, 2005).

2.4.2 Prevalence and mortality

According to the IDF (2015), 415 million people worldwide or 8.8% of adults aged

20–79 years were estimated to have diabetes in 2015. This is equivalent to 1 in every 11 adults. This is expected to rise to 642 million or 1 in every 10 adults by 2040 (*ibis*.). The prevalence rate is rapidly increasing due to widespread obesity and sedentary lifestyles (typical effect of westernisation of life), as well as younger age at diagnosis and longer survival (Bilous & Donnelly, 2010).

In 2015, diabetes was accountable for 5 million deaths, or 14.5% of global all-cause mortality amongst adults, and almost half of these deaths were in people less than 60 years of age (IDF, 2015). In fact, diabetes and its complications are considered to be major causes of premature mortality in many countries. According to the WHO (2009), hyperglycaemia is the third highest risk factor for early death, after high blood pressure and tobacco use. Cardiovascular disease causes between 50% and 80% of deaths in people with diabetes.

2.4.3 Managing diabetes

The main aim in the management of diabetes is to lower blood glucose, as well as the levels of other factors known to damage blood vessels (WHO, 2011). Moderating blood glucose may be partly achieved through the administration of oral hypoglycaemic agents (in Type 2 diabetes) and/or insulin (in Type 1 and Type 2 diabetes). Measures are also needed to screen for and control high blood pressure and abnormal lipid profiles. Other interventions involve foot care for the prevention, detection and management of foot complications, together with screening and treatment for eye and kidney complications. As suggested by the WHO (2011), these measures should be supported by healthy eating, regular exercise, maintaining a normal body weight and non-smoking. All these lifestyle, medical and monitoring interventions form an essential part of diabetes self-management. It is important to note however, that these interventions only address the physical impact of diabetes on the individual and that they themselves may impose psychological and sociological consequences which need to be dealt with on a daily basis. Nonetheless, the importance of these interventions and their impact on diabetes control will be discussed in the next sections.

2.4.4 The effect of blood glucose control on the development of diabetes complications

Once the association between hyperglycaemia and long-term diabetes complications became evident, clinical trials were carried out to study how diabetes management, aimed at maintaining tight glucose control, may prevent the development of these complications. Two major trials carried out with this aim were the Diabetes Control and Complications Trial (DCCT) involving 1,441 individuals with Type 1 diabetes (DCCT Research Group, 1993) and the United Kingdom Prospective Diabetes Study (UKPDS) involving 3,867 individuals with Type 2 diabetes (UKPDS Research Group, 1998a). These were large multi-centre trials, the results of which had a huge impact on protocols related to diabetes management.

Both these clinical trials were robust, involving a large number of individuals recruited from multiple centres. Allocation of subjects was carried out by random methods. Despite long follow-up periods, dropout rates were extremely low. Both studies found that a significant reduction of blood glucose achieved through intensive treatment, was associated with a statistically significant reduction in the occurrence of microvascular complications. However, reductions in macrovascular complications did not reach statistically significant levels. This may be due to the fact that macrovascular complications result from factors other than hyperglycaemia, such as hypertension and hyperlipidaemia (Stratton *et al.,* 2000).

This observation was supported by the UKPDS Hypertension Study which took place among a cohort of individuals participating in the UKPDS main study (UKPDS Research Group, 1998b). This study showed that those who controlled their blood pressure besides their blood glucose, had a significantly greater reduction in the risk of macrovascular complications. This goes to show that, in line with recommendations from the WHO (2001) as quoted above, for preventing macrovascular complications, controlling for risk factors other than hyperglycaemia, is crucial in diabetes care (Stratton *et al.,* 2000). This increases the demands on the individual and renders diabetes management more challenging and complicated.

2.4.5   Self-management behaviours and blood glucose control

Behavioural issues are thought to influence diabetes management by helping to control blood glucose levels. These behaviours include adhering to medication and dietary regimens, exercising and self-testing.

Although the DCCT and UKPDS trials have convincingly shown that tight glucose control may delay the onset of diabetes complications, in these studies the emphasis was on the outcome of a particular approach to medical management of diabetes. Considering that behavioural issues are thought to influence diabetes management, this section will review studies which have examined the impact of these behaviours on glucose control, regardless of the medical management involved. The design of these studies included cross sectional designs (Schectman *et al.*, 2002; Heisler *et al.,* 2003; Daly *et al.,* 2009; Khattab *et al.,* 2010), and a behavioural intervention study (Jones *et al.*, 2003).

These studies analysed each behavioural domain separately and examined the extent by which each behaviour was independently associated with a lower level of glycated haemoglobin (HbA1c), after controlling for confounders. HbA1c is a blood test, the result of which represents an average concentration of glucose during the last 3−4 months before the test is carried out (Motta *et al.,* 2010). Across these studies, patients with both Type 1 and Type 2 diabetes were included. Taking medications (Schectman *et al.*, 2002; Heisler *et al.,* 2003; Daly *et al.,* 2009; Khattab *et al.,* 2010), healthy eating (Jones *et al.,* 2003; Heisler *et al.,* 2003; Daly *et al.,* 200; Khattab *et al.,* 2010), exercising (Heisler *et al.,* 2003; *Khattab et al.,* 2010) and self-monitoring (Jones *et al.,* 2003; Heisler *et al.,* 2003; Daly *et al.,* 2009; Khattab *et al.,* 2010), were all found to be independently associated with a lower level of HbA1c, highlighting the importance of these behaviours in self-management. An important limitation of most of these studies was the use of self-report measures in examining behaviours. This may lead to inaccurate results due to factors, such as poor recall, inaccurate perception of one's behaviours and an inclination to give socially desirable answers (Heisler *et al.,* 2003). Also, most studies were observational. Therefore, they could not determine whether the association between self-management behaviours and glycaemic control was causal or not (Karter *et al.,*

2001). A strength across these studies was the large sample size used, which allowed statistical significant differences to be identified despite controlling for a number of possible confounders. The smallest sample size reported was that of Daly *et al.* (n=253). Sample sizes of the other studies were larger than 800 respondents.

The above sections have highlighted the importance of self-management in achieving positive diabetes outcomes. However, the difficulties encountered by the individual in maintaining tight glucose control cannot be underestimated. The sections below will look closer at this issue.

2.4.6   Individuals' experience of diabetes self-management

When one looks at the range of recommendations that individuals with diabetes are given about lifestyle issues, it is easy to imagine that to the individual with diabetes, its management may look complex and restrictive. Moreover, as previously stated, disease self-management involves more than just an array of behaviours to be learnt and practised. Individuals have to cope with the various psychological, emotional and social consequences associated with their condition and its management, striving in the process, to maintain important social roles and life commitments. Diabetes self-management may thus become an onerous task.

Diabetes-related experiences have been examined by studies which have explored these from the perspective of individuals with diabetes themselves. Results of these studies will not be analysed here, but rather, they will be discussed and compared to findings from this study in the following chapters. Nevertheless, a brief overview of these findings is given in this section.

Studies exploring the lived experiences of diabetes have found various challenges which individuals with diabetes have to face on a daily basis so as to manage their condition. These range from problems with changing their lifestyle, with building therapeutic relationships with their health professionals, as well as problems related to accepting their condition and adopting a positive self-image despite having diabetes. Problems seem to be multi-dimensional, arising from patients' perceptions of diabetes and its management, from the progressive nature of diabetes itself, and

from various aspects of the socio-cultural and political context. Difficulties at a general level seem to cross geographical and cultural boundaries, although the way by which these are experienced have been found to be different across cultures.

The complex and demanding nature of diabetes self-management calls for the need to support individuals in this challenging experience. The goal of support provision is to help persons make informed choices and achieve self-selected goals regarding their long-term condition (Sarkadi, 2001). Such support for self-management is viewed as an important way to address the disease burden related to diabetes (Furler *et al.,* 2008). In fact, studies conducted in this area have identified a positive relationship between support provision and diabetes-related coping. For example, Karlsen *et al.* (2004) in their cross-sectional study involving 534 Norwegian adults with diabetes, found social support from family and health professionals to be significantly related to various positive forms of coping with diabetes. The question remains as to what type of support individuals require and whose opinions should be sought to make decisions regarding the nature of support which should be provided. The sections which follow address these issues.

2.4.7   Sources of self-management support

The major source of support, which is addressed in the literature, is that provided through self-management education programmes. In diabetes care much evidence exists to support the importance of such programmes in improving disease management. Systematic reviews analysing this evidence and consolidating positive outcomes of these programmes, include those conducted by Heinrich *et al.* (2010), Minet *et al*. (2010), Avery *et al.* (2012), Dube *et al.* (2015), and Sherifali *et al.* (2015). Notwithstanding this, those systematic reviews which analysed the relationship between duration of follow-up and measured outcomes, found that the effect of educational interventions decreased over time (Norris *et al.,* 2002; Deakin *et al.,* 2005; Minet *et al.,* 2010). Similar results were obtained by Khunti *et al.* (2012) who examined the long-term effectiveness of the diabetes education and self-management programme for ongoing and newly diagnosed individuals (DESMOND) in the UK. Thus, the long-term effectiveness of these programmes remains debatable. Consequently, such programmes alone may not be sufficient to

help clients maintain a desirable level of self-management and well-being, and other sources of support may be needed.

With reference to an ecological approach to self-management support, Fisher *et al.* (2005), point to the central role which various factors within the individual's physical and socio-political environment may play in supporting self- management. A typical example would be access to healthy food and family support in order to carry out the necessary dietary modifications required. This argument is supported by findings of studies, which have highlighted the multi-dimensional nature of problems inherent in diabetes experiences (e.g. Vermeire *et al.*, 2007; Gomersall *et al.,* 2011). An ecological approach to support provision also acknowledges that individuals' choices are often dependent on factors which are outside the individual's immediate control. While the need for multiple sources of support is often acknowledged, information about the nature of this support is needed at both political and clinical level to facilitate self-management. The next section addresses the central role which patients have in providing this information.

2.4.8   Patients' expressed need for support

It is increasingly acknowledged that service development requires that the consumers are allowed to voice their opinions and express their needs regarding the service in question (Pencheon, 2006). This is important in healthcare, where perceptions of need amongst service users may vary from those of service providers. For instance, beliefs and perceptions on diabetes and its management amongst patients and their care givers have been repeatedly found to differ (Clark & Hampson, 2003; Fitzgerald *et al.,* 2008; Wu *et al.,* 2014). Hence, as stated by Peyrot (2013), perspectives of patients with diabetes are important in informing all levels of health policy and care. In fact, patient and public involvement in decision making has become a central feature in the healthcare systems of various western democratic countries (Petsoulas *et al.,* 2015).

Notwithstanding the above arguments, in the field of diabetes care, interest in examining support needs as articulated by patients, has mostly emerged during the last decade. Studies have been mainly conducted in the American, Australian and

European regions, though different cultures have been studied. Most of the work carried out to explore individuals' views of support provision, is qualitative (e.g. Sturt *et al.,* 2005; Vincent *et al.,* 2006; Morris *et al.,* 2006; Savage *et al.,* 2009; Turner, 2008) although quantitative research in this area has also been conducted *(*Richmond, 2006; Sarkar *et al.,* 2008; Gorter *et al.,* 2010; Schiøtz *et al.,* 2012). Qualitative studies have relied almost exclusively on the use of focus groups for data collection, pointing to a limitation in this area of research. Focus groups provide a 'public' context for data collection and such situations may elicit data which is different from those obtained 'privately' during a one-to-one interview (Farquhar, 1999). Also, focus groups are known to obtain breadth of information and this may result in missing out on an in-depth understanding of phenomenon (Krueger, 1994). Another limitation is that the vast majority of these studies were aimed at identifying expressed educational needs. Here, individuals are asked how they would like to receive educational interventions which best suit their self-management needs. As previously mentioned, although educational measures are important, they may be limited in supporting self-management. Nonetheless, limited work has been conducted to explore expressed need for support other than that which is educational, pointing to a literature gap in this area.

A more recent approach towards studying diabetes support need is through exploring individuals' experiences of factors which hinder or facilitate their diabetes self-management. The researcher then identifies support measures which may address these experiences. Studies using this approach have been carried out across the globe, and the approach to investigation has been almost exclusively qualitative, using either in-depth interviews or focus groups (e.g. Song *et al.*, 2010; Hasseler *et al.*, 2011; Fort *et al.*, 2013; Nguyen & Edwards, 2014). Reviews or meta-synthesis of the literature available in this area have also been conducted (Nam *et al.,* 2011; Stiffler *et al.*, 2014; Wilkinson *et al.*, 2014; Yuncken, 2014; Sohal *et al.,* 2015). The advantage of this approach to investigating support need is that of constructing related knowledge upon in-depth exploration of the lived experiences of diabetes. However, this approach may overlook the manner by which participants may wish that their experiences be addressed through health services or other public policy interventions. These issues are often decided upon by the researcher him/herself.

The present study has sought to explore expressed need for self-management support, using methods which address the limitations and gaps in the available evidence, as outlined above. It used different methods of data collection, involving a combination of focus groups and one-to-one interviews, so as to obtain both breadth and depth of information. It explored support needs other than educational ones, avoiding the assumption that individuals would perceive educational support as their major need for self-management. Furthermore, it explored the lived experiences of participants, through identifying perceived barriers and facilitators to self-management, while also examining participants' views of how local services or policies may render their experiences more positive. These objectives and methods are addressed in more detail in the following chapters. Before that, a description of the context where this study took place is given in the next section.

2.5   The Maltese context

This section first describes geographical and cultural aspects of Malta where this study was carried out. This is followed by information about diabetes in Malta. More detail of the local context will be given in the following chapters and this will be discussed in light of the findings of this study.

2.5.1   Malta: Geography and culture

Malta is a southern European country forming an archipelago with another two smaller islands, and is situated in the Central Mediterranean, south of Sicily. With a size of a mere 316 square kilometres and a population of about 425,000 (National Statistics Office (NSO), 2014) it is one of the most densely populated countries in the world (Grixti, 2006). As with other European countries, Malta has an ageing population. In 2012, those aged 65 or older represented 16.4% of the population (EUROSTAT, 2014).

Because of its location, Malta has been strategically advantageous for the domination of the Mediterranean, which is why, over the centuries, it has been at the centre of various conflicts and ruled by a number of nations including the Phoenicians, Arabs, French, British and Italians (Grixti, 2006). All of these have left genetic and cultural

imprints amongst the Maltese population. Malta became an independent nation in 1964 and joined the EU in 2004. Maltese, a Semitic language written in Latin alphabet, is the first official language, and English, which is also widely spoken, is the second official language. Despite an increased trend towards secularisation, the Maltese are generally Roman Catholics (98%) with religion still having an important place in society (Mitev, 2011a). The Maltese population is largely homogenous, although there has been an increased influx of foreigners over the past few years. The NSO (2016) reports that in 2014, 7.4% of the local population were in fact foreigners. The economy of Malta is mostly dependent on foreign trade, manufacturing and tourism (Grixti, 2006).

Although broadly Mediterranean, Maltese culture is distinctive (Formosa *et al.,* 2012), being influenced by its history and religion, as well as tourism and the media. In fact, the Maltese still hold tight to certain traditions related to religion, social life, family and *festa* (Baldacchino, 2011). For example, a good number of women still hold traditional female roles of motherhood and homemaking. In fact, Malta has a very low percentage of working women, which stood at 40.6% in 2015 (National Statistics Office, 2016). The Maltese enjoy eating out with family and hold religious celebrations all year round, with food being consistently a central theme. For example, the village *festa*, which is central in defining Maltese culture, is held yearly in every town and village in celebration of the town's patron saint. On these occasions, village squares and streets, which are highly decorated, become hubs of bustling activity, including village bands, food stalls and spectacular fireworks. In the following chapters, specific cultural elements will be described and discussed in relation to the findings of this study.

2.5.2   Diabetes in Malta

Diabetes is highly prevalent and poses a significant health problem in Malta (Cuschieri & Mamo, 2014). The last population based survey which measured the prevalence of diabetes was carried out in 1981 by the WHO, finding a prevalence rate of 7.7% (Katona *et al.,* 1983). Since then, published prevalence rates for diabetes in Malta have been based on estimations. This is calculated to be 13.9% amongst adults, compared to the European average of 9.1% (IDF, 2015). A

population based prevalence study is currently underway.

2.5.2.1   *Historical and current contributors to high diabetes prevalence*

Diabetes has been documented in Maltese medical literature since the eighteenth century (Savona-Ventura, 2001). However, it was not until the 1950s that diabetes started to be considered as a national public health concern (Formosa *et al.,* 2012). By 1955, the recorded diabetes mortality rate was the highest in the world, with 26.1 deaths per 100,000 population (Cassar, 1982). In 1961, diabetes was declared as the "national disease of Malta" and a decision was made to tackle this problem "vigorously" (Cassar, 1982, p. 20). The high prevalence of diabetes amongst the Maltese population has been attributed to a number of factors, amongst which are a genetic predisposition and close family relationships due to inter marriages commonly occurring in small islands (Formosa, 2009). Also, historical trends in the diet of Maltese individuals are thought to have increased the risk of developing diabetes. This is explained below.

Because of its limited agricultural land, Malta has been historically dependent on the importation of food and because of this, compounded with the generally low socio-economic status of the general population, the Maltese community have gone through phases of food deprivation, particularly during World War II (Formosa *et al.,* 2012). This is thought to have led to the development of the Thrifty Diet Phenotype amongst the Maltese population, which acted as a protective mechanism to help individuals adapt to long periods of starvation (Savona-Ventura & Scerri, 2012). According to the thrifty genotype hypothesis, which has been supported by epidemiological evidence, this phenotype presents no problems just as long as the population remains lean. However, a child born with a thrifty phenotype is likely to develop metabolic disorders, such as Type 2 diabetes, if he/she grows up in an affluent environment, since his/her physiology would not be adapted to the over-consumption of food (Hales & Barker, 2013). This is what happened to children born to Maltese mothers who had suffered periods of food deprivation. After the war, and accompanying an improvement in social and financial conditions, food became more abundant. Maltese people did not only consume more food, but under the influence of the British, switched from a Mediterranean diet, to one rich in fats

and refined carbohydrates (Cassar, 1982). This led to obesity, an increase in peripheral insulin resistance and hence an increase in diabetes, amongst those born with the thrifty phenotype (Neel *et al.*, 1998).

Having shifted away from the Mediterranean diet, Maltese individuals today consume significant amounts of processed meats and other processed food, which are high in fats, sugar and salt (Ministry for Health, the Elderly and Community Care, 2010). Moreover, Maltese adults report low levels of physical activity. During the last European Health Interview survey carried out in 2008, only 43% of the adult population reported carrying out moderate or high level of physical activity (Department of Health Information and Research, 2008). This lifestyle pattern increases the risk of obesity amongst the Maltese population. In fact, the European Health Examination pilot survey, conducted in 2010, measuring the Body Mass Index (BMI) of 221 subjects, found 66% of those aged 25–64 to be overweight or obese (Directorate for Health Information and Research, 2012). The combination of historical developments, genetic predisposition and present lifestyle patterns are likely to be contributors to the high prevalence of diabetes amongst the Maltese today. This has resulted in a negative impact on the health of those affected, as will be shown in the following section.

2.5.2.2   *Health of individuals with diabetes in Malta*

Various health indicators of the Maltese population have shown that the health of individuals with diabetes is poorer, compared to that of other members of society. In fact, the high prevalence of diabetes in Malta contributes significantly towards population morbidity and mortality (Rocchiccioli *et al.,* 2005) and bears an economic burden to Maltese society (Ministry of Energy and Health, 2014a). Epidemiological data supporting these statements have shown that the self-reported Mean Health Index is significantly lower in people with diabetes, compared to individuals without this condition (Department of Health Information and Research, 2008). The average age of death due to diabetes in 2013 was lower than that of the general population, being 72.2 years in males and 77.9 years in females compared to the general population's median age at death of 73.5 years and 79.3 years respectively (Directorate of Health Information and Research, 2015). Also, in 2011,

the average length of stay in hospital for diabetes was high, recorded to be 13.7 days, compared to the EU average of 8.5 days (Ministry of Energy and Health, 2014) and compared to 5 days amongst the rest of the Maltese population (NSO, 2013).

Small scale studies have been carried out to measure health indicators amongst Maltese individuals with diabetes. Cross-sectional studies were carried out by Grima (2009), Bugeja *et al.* (2009) and Cutajar (2008), involving 313, 149 and 110 participants respectively. Individuals for the three studies were chosen by convenience sampling from public health clinics/departments. The three studies found a mean HbA1c higher than the 6.5%, as recommended by the WHO (2011) (7.95, 8.02 & 7.32 respectively). The studies also found a high mean BMI (29.5, 30.55 & 27.9 respectively) when the normal BMI according to the Centre for Disease Control and Prevention (CDC) (2013) is 18.5–24.9. Grima (2009) and Cutajar (2008) found that the majority of their participants suffered from hypertension, and the average Low Density Lipoprotein (LDL) level among their samples were also high (3.14 & 3.49 respectively, normal LDL according to CDC (2015): < 2.59 mmol/L). Diabetes-related knowledge amongst participants was found to be poor (Grima, 2009; Cutajar, 2008). These findings need to be interpreted in the light of limitations inherent in sampling methods and relatively small sample sizes used by some of the authors, with none of the studies giving confidence intervals for their findings. Nonetheless, the available evidence demonstrates the need for a change in the current management of diabetes and perhaps an improvement in local support services.

2.5.3   Diabetes-related services in Malta

This section gives a brief overview of the diabetes services which are available in Malta. More detail will be given when discussing related findings in Chapter 8.

In Malta, public healthcare is free of charge at the point of use, and is funded through taxation and national insurance. The public health sector is the main provider of health services. Here, diabetes follow-up care is either provided at the Diabetes and Endocrinology Unit in the Outpatients Department of Mater Dei

Hospital (the only public acute general hospital on the island), or at diabetes clinics located in health centres in various localities around the country. Follow-up care for monitoring diabetes and reviewing treatment is only carried out by members of the medical profession, whether general practitioners (GPs) or specialists. In Malta, there are only two diabetes nurse specialists and they are mostly involved with patient education as opposed to reviewing patient treatment. Diabetes follow-up care is also provided in the private sector by GPs and medical diabetes specialists who work in solo practices which do not generally employ nurses or other allied health professionals. Private care is largely paid out of pocket and it is up to the patient to choose between private and public healthcare. In the private sector, patients have direct access to medical diabetes specialists, without the need for a referral.

Whilst medications and insulin syringes are generally distributed for free, this is against a number of restrictions. For example, not all diabetes medications are included in the Government Formulary List, and hence not all are available free of charge. Conventional syringes rather than insulin pens are generally provided for those with Type 2 diabetes. Self-testing equipment is only given free of charge to individuals with Type 1 diabetes. A National Diabetes Strategy was only recently set up in December 2015 (Ministry of Energy and Health, 2015).

2.5.3.1 *The patient pathway in diabetes care*

Upon being diagnosed with diabetes (by a GP or during a hospital stay/visit), patients are immediately referred to the diabetes clinic of the nearest health centre. Here, patients are assessed by a GP who initiates a management plan and registers the patient to receive free drugs if necessary (registration for free diabetes drugs can only be carried out at the public health sector). Referrals to foot and eye screening and an appointment with a dietician are also made. Patients are then referred to the Diabetes and Endocrinology Unit at Mater Dei Hospital where they are reviewed by a medical diabetes specialist who decides where follow-up should continue. This would depend on the type and severity of diabetes. Patients with Type 1 or uncontrolled Type 2 diabetes will continue to be reviewed by medical diabetes specialists at Mater Dei Hospital, while individuals with well-controlled Type 2 diabetes are followed up by GPs at community health centres. Patients can

eventually be transferred between hospital and community clinics if and when their diabetes control changes. If the patient so prefers, follow-up can take place at private clinics.

Screening for foot and eye complications continue at community or hospital-based clinics, depending on where follow-up consultations take place. Patients are referred to a structured diabetes education programme held at Mater Dei Hospital. Those with Type 1 and gestational diabetes are also referred to a diabetes nurse specialist for individualised education, but for those with Type 2 diabetes this happens only if and when they are switched to insulin treatment. In the public sector, referral and appointments for follow-up consultations, screening and education are not always regular and timely. More detail about this will be given in Chapter 8.

2.6   Conclusion

This chapter has highlighted the negative impact which diabetes has on the health and economy of nations. It has also presented and discussed evidence which shows that effective diabetes management may prevent complications and improve disease prognosis. However, diabetes self-management tends to be a complex activity and its implementation and integration in everyday life may prove challenging for individuals with diabetes, which is why these require support for self-management. Although educational support has been found to be useful, its influence of self-management is limited, underlining the need for other measures of support which address challenges, such as those originating from within the socio-cultural context. Although research has focused on identifying perceived support needs amongst individuals with diabetes, gaps in this evidence have been identified. This study has sought to address these gaps.

This chapter has highlighted the impact of diabetes on the health of the Maltese community. It has pointed to various national characteristics, such as history, culture and lifestyle which may partly explain the high prevalence of this condition in Malta. These characteristics may also signify important challenges to diabetes self-management which is what this study has set out to explore. The methodological approach used in this investigation will be discussed in the next chapters.

Chapter 3

METHODOLOGY

3.1   Introduction

This study has sought to explore what life with diabetes is like for Maltese individuals who have this condition. More specifically, it set out to uncover views held by these individuals, about how they could be supported to manage their diabetes. The aim was to discover not merely the nature of these views, but also the social conditions which lead to them. Chapters 3 and 4 describe the journey to this discovery. They explain the methods I used to study people's views and the reasons for choosing these procedures.

This chapter presents the methodology of this study, focusing on the philosophical principles upon which I selected my approach to investigation. Reference is first made to the research question and objectives. The chapter then presents the epistemological and ontological principles which led me to choose my research paradigm. It also discusses my decision to using GT to guide my research, outlining the theoretical underpinning of GT, and its relevance to this study. Finally, central concepts and general features of GT are described and discussed with reference to how I addressed these features in my methods.

3.2   Research aim and objectives

Decisions regarding methods for this study depended primarily on the research question and objectives. These are outlined below.

3.2.1   Research question

What views do Maltese individuals with Type 2 diabetes have regarding their needs for diabetes self-management support?

3.2.2 Research objectives

The research objectives of this study were as follows:

1. To explore what Maltese individuals with Type 2 diabetes experience and understand by diabetes self-management.

2. To identify factors which individuals with Type 2 diabetes view as facilitating or hindering diabetes self-management.

3. To explore what preferences and recommendations individuals with Type 2 diabetes may have regarding support for diabetes self-management.

4. To explore how cultural and socio-political issues may be related to individuals' views about diabetes self-management support.

As indicated above, this study has focused only on perspectives of individuals with diabetes. It is acknowledged that there are advantages associated with studying different perspectives of self-management support needs, including for example, those of healthcare professionals. However, I decided to focus only on individuals with diabetes as they would have first-hand experience of their needs, which may indeed be complex. Focusing solely on this perspective would enable me to explore it in greater depth. Notwithstanding this, it is acknowledged that this study does not represent a comprehensive picture of views on support needs for diabetes self-management in Malta.

3.3 The research paradigm

The methodology for this study was chosen after reflecting on the central concept within the research questions, namely diabetes self-management support. I held fundamental assumptions about this concept, which were shaped by specific ontological and epistemological principles. These principles are presented in the section below, indicating how they led to the choice of a specific paradigm, which acted as a framework to this study. As stated by Neuman (2006), paradigms link abstract issues in philosophy to concrete research techniques. This paradigm thus guided my choice of methods.

3.3.1 My assumptions about diabetes self-management support

I set out to carry out this study believing that views about self-management support may vary amongst different individuals. For example, while the perceived need for diabetes information may be common to all, different individuals may hold varied views about what constitutes effective information. Individuals' views about self-management support may, in turn, be related to or 'constructed' on the basis of their experience with living with diabetes, as well as the context in which they live. Thus, these views may form 'subjective realities' about self-management support. These assumptions are in line with philosophical underpinnings of the interpretive paradigm, in particular with the social constructivist worldview. According to social constructivists, reality is what people perceive it to be. It is subjective, varied and multiple and is constructed through social interaction (Creswell, 2009). Thus, as suggested by Rubin and Rubin (2005), for the interpretive constructivist researcher, the person's view of a phenomenon and the meaning he/she attributes to it, is what is important. Also, as Rubin and Rubin (2005, p. 28) continue to state, because meaning is constructed through social interaction, constructivists often "pay attention to shared meanings held by those in a cultural arena."

The interpretive paradigm is associated with qualitative methods of research and these have been chosen to guide the design of this study. These methods involve an in-depth exploration of a phenomenon whereby the researcher seeks to understand complexity of views (Bryman, 2008). This requires that questions asked would be broad and open ended, so that the participants can express their thoughts (Creswell, 2009). The ultimate purpose is 'to develop an understanding of social life and discover how people construct meaning in natural settings' (Neuman, 2006, p. 88). The act of discovering and making sense of the meanings of others involves the generation of a theory or pattern of meaning (Creswell, 2009). Thus, as Crotty (1998) concludes, this qualitative approach becomes largely inductive.

After choosing the interpretive paradigm and qualitative methods of investigation, I had to decide on the specific approach to qualitative research, which best suits the aim of this study.

3.4   Using Grounded Theory

The choice of GT as an approach to qualitative enquiry was based on the premise that people develop views about self-management support upon their experience of living with diabetes within a specific socio-cultural context. Individuals build their ideas about what hinders or helps their self-management through various interactions. These would include interactions which they have with others (such as carers, friends and family) and with their environment from which they seek various resources. In other words, developing views about self-management support involves a process. This line of thought was the trigger for choosing GT to guide methods. As stated by Charmaz (2009) and Strauss and Corbin (1998), GT is a method to study or generate an explanation of a social process. Bluff (2005) also states that GT seeks to understand and eventually develop a theory of how individuals and groups create meaning together and interact with each other. Thus this approach was thought to help explore interactions experienced by individuals with diabetes, in order to provide in-depth understanding of how expressed needs develop from these interactions. In doing so, it would help to inductively develop a theory about how perceived need for support may emerge from within the context being studied.

It was important at this stage to understand an essential difference between GT and other qualitative approaches to investigation. Holton (2010) emphasises the role of GT in abstraction. She stresses how, unlike other qualitative methods, GT does not seek to achieve accurate description of phenomena but rather, it seeks to develop conceptual abstraction of these in the process of developing a related theory. Thus, the aim for this study was to use GT in order to explain, through theory formulation, how living with diabetes in Malta may give rise to specific needs. This would involve choosing methods which enable me to discover latent forms of thinking and interacting, which are relevant to participants' experience of diabetes. During data analysis, developed themes or categories would be conceptualised and combined, in order to develop an explanatory theory. It was understood that these methods were unique to GT.

3.5   Historical perspectives of Grounded Theory

Grounded Theory as a method of research was developed in the 1960s by Barney G. Glaser and Anselem L. Strauss. Their first publication about this method, in 1967, referred to a grounded theory as being discovered from data, which is systematically collected and analysed (Glaser & Strauss, 1967). The authors were keen to demonstrate how systematic qualitative research could produce evidence which is of equal significance to that produced by quantitative methods and which were highly predominant at that time. They proposed, however, a system of investigation, which contrasted with that used in quantitative studies. They challenged the perception that research is about deductively testing pre-existing theories. They proposed that researchers could inductively develop new theories from data, insisting that such theory should be *grounded* in data. In doing so, they also moved qualitative inquiry beyond descriptive studies into studies which produced explanatory theoretical frameworks (Charmaz, 2006).

Bryant and Charmaz (2010a, p.50) write about how, years after the discovery of GT, it "came under fire both from within and without the GT community." As the authors continue to state, some scholars labelled the methodology as "naïve inductivism." This was partly due to the fact that Glaser and Strauss failed, in their original work, to address problems related to the inductive process. Others labelled it as 'positivist' because of the 'objectivist' stance they took in relation to non-problematic data. Their work (particularly Glaser's) had objectivist underpinnings, assuming an external reality and a neutral observer who 'discovers' it in the data. As a reaction to this, some scholars have sought to adapt aspects of GT, pointing to how an altered approach may overcome these criticisms. Over time, many researchers have adopted and adapted GT to reflect various ontological and epistemological positions. An increasingly popular position is that of constructivism. This has eventually led to the division between the 'objectivist' (also known as 'classic') and 'constructivist' GT. Constructivists claim that their aim was to remodel GT methods in the light of the current philosophical and epistemological ideologies, while preserving core elements without which GT would lose its identity (Bryant & Charmaz, 2010a). Bryant and Charmaz (2010a, p. 51) call this new method of GT a

'repositioned' GT. Differences between the 'objectivist' and 'constructivist' GT methods will be described at a later stage.

The various proponents of GT today, have their own prescriptions of how to use the method. This has led Dey (2004) to explain that today, there is no single, unified methodology which researchers can follow. However, central concepts from Glaser and Strauss's original work remain, and theories arising from research which addresses these concepts still qualify as Grounded Theories.

3.6 Theoretical underpinnings of Grounded Theory

GT derives its theoretical underpinnings from Symbolic Interaction, which denotes that reality of the self and the environment is socially constructed. The theory is based upon the original work of George Herbert Mead, a social psychologist who was influenced by American pragmatism (Crotty, 1998; Jeon, 2004). This philosophical movement is marked by the belief that the meanings of conceptions is to be sought in their practical consequences and that the function of thought is to guide action (Aune, 1970). Many scholars have used the teachings of Mead's student, Herbert Blumer who further advanced Symbolic Interaction and gave it its name (Jeon, 2004). Blumer (1969) describes individuals' behaviour as being based upon three main processes:

1. Humans behave toward things according to the meaning they attach to these things.

2. Humans create these meanings upon social interaction.

3. The meanings humans attach to things are modified through their interpretation of the signs (or symbols), which they encounter.

As shown above, while holding the principle that meaning is central to human behaviour, the theory of Symbolic Interaction provides a basis to understand how people establish this meaning from social interaction. During interaction, language is often used as the unit of symbols which need to be interpreted. Language is commonly the means by which people negotiate meaning. Moreover, thought is

needed for interpretation of symbols, and is thus also involved in the formulation of meaning. Blumer (1969) holds that the interpretive process and the context in which it happens are a vital element in the person's formation of meaning. Thus, within the theory of Symbolic Interaction, humans are seen as "active, creative participants who construct their social world, and not as passive, conforming objects of socialisation" (McClelland, 2000, p. 1).

The theorising of social behaviour as outlined above, explains the link between Symbolic Interaction and GT. According to the theory of Symbolic Interaction, there is a whole process involved in constructing meaning and in shaping behaviour. GT is all about studying this process. It is about studying how individuals interact with each other and construct meaning together. In this respect, Symbolic Interaction and GT have strong compatibilities. As Bryant and Charmaz (2010a) explain, both GT and the theoretical perspective underpinning it, assume an active, rather than passive agent. Also, they both emphasise the significance of studying a process which is determined by the context in which it takes place. To this extent, Grounded Theories about social life are often 'conditional' that is, they become dependent on specific social conditions and are modifiable as these conditions change (Bryant & Charmaz, 2010a). The notion that context is so important in shaping meaning and behaviour, signifies the very need of this study and potential uniqueness of its results.

The theory of Symbolic Interaction was considered relevant to this study as it was seen as a way to help me understand how Maltese people develop meanings related to diabetes in their lives, and how these meanings eventually lead to perceptions of need. This would involve amongst others, examining interactions between participants and significant others such as family; exploring interpretations of these interactions by participants, such as whether and how these are helpful/unhelpful; and identifying perceived needs which emerge from these interpretations. Besides guiding my approach towards examining diabetes-related experiences, the theory of Symbolic Interaction influenced other methodological decisions. These will be outlined in this, as well as the next chapter. However, despite the relevance and usefulness of this theory to my study, consideration was also given to the potential

limitations involved in allowing this theory to guide my work. These are presented in the section below.

3.6.1   Basing the study on Symbolic Interaction - potential limitations

Glaser and Strauss (1967, p. 46) suggested against having a strong commitment to "one preconceived theory." In fact, despite the strong link between GT and Symbolic Interaction, Holton (2010) cautions the reader that basing one's research methods on a specific theory may interfere with the issue of entering the research without preconceived ideas, this being a central issue in GT. Holton (2010, p. 269) states that:

> Pre-framing Grounded Theory through the theoretical lens of Symbolic Interactionism precludes other perspectives … and limits [amongst others] the analyst's creativity in the analysis and conceptual abstraction of the data under study.

Holton (2010) continues to state that adopting only the epistemology within Symbolic Interaction pushes the researcher onto focusing on the importance of context. Holton (2010) writes this from the classic GT's perspective, for which, she states, context is merely another factor which may feature within a social process, without necessarily influencing it.

I have reflected upon the above argument, acknowledging that I had set out to study views about the need for support and considering 'context' as being central in the formulation of these views. Nonetheless, at the outset of the study, I reflected upon my standpoint on the issue of context and the way this may influence my methods. It was felt that focusing on factors within the individuals' social environment may force me to overlook factors related to perceived need which may fall outside this context. The cautionary note made by Holton was taken up. Upon reflection, I believed that the extent by which emphasis on context would limit and predetermine my methods, would depend on my perspective of context. So, the following questions were reflected upon: What is context about in this study? What does it include or exclude? Thought was given about the possible factors that may determine individuals' perceived need, and the relationship of these to context. I reflected on

factors whose relevance to the social context may not be straightforward. For example:

1. Although the Theory of Symbolic Interaction stresses upon the *social* context, factors within the physical environment may impinge on the development of need. These may include aspects such as poor access to healthy food or having nowhere to exercise. However, although these factors are within the physical environment, they are often determined by the socio-political one. So, it was considered that even here, the social context becomes relevant.

2. Intrapersonal factors may also be central to determining views about need. Individuals may feel that they lack the ability or the confidence to carry out behavioural change. At face value, these factors did not seem related to context. However, feelings about oneself may be consolidated through interactions with others. For example, negative talk by health professionals about unsuccessful efforts towards behavioural change may demoralise the patient and challenge his self-confidence. As Mead and Morris (1962) assert, people build an understanding of the 'self' upon interaction with the social world. Therefore, even in relation to intrapersonal factors, the social context again remains relevant.

In light of arguments put forward above, I considered context to remain consistently significant and to include all that goes on in the life of participants which impinges on self-management. Care was taken to allow factors perceived as significant to participants to emerge during interviews, whether these were of an intrapersonal, social or environmental origin as all these would be somehow related to context. Also, effort was placed to identify these factors during analysis. Using a wide definition of context was relevant to the concept of an ecological approach to diabetes self-management support (Fisher *et al.,* 2005). This places emphasis on both intrapersonal factors and all aspects of the individuals' environment which may determine need.

3.7   Central concepts in Grounded Theory

3.7.1   Theory construction

Theorising is the central purpose of GT (Bryant & Charmaz, 2010b). The procedure is characterised by the development of categories from data. This involves using an

iterative process of going back and forth between data and categories, rendering the latter progressively more focused and abstract *(ibid)*. Theories will then emerge from linking abstract categories together, through finding relationships between them. The manner by which I employed these procedures to develop my theory will be explained in the next chapter. This section will address types of grounded theories and the role of grounded theory in explaining causation.

GT literature refers to 'substantive' and 'formal' theories. Substantive theories are grounded in concrete social situations and are closely linked to the practice domain (Locke & Locke, 2001). Substantive theories cannot generalise beyond the situation from which they were developed. Formal theories develop from substantive ones. They function at a higher level of generality. Glaser (2010) states that the development of formal theory involves generalising the implications of a core category developed from substantive theory. He states that "[Formal theory] extends the core category in breadth and depth to more substantive areas within and without, or beyond, the original area." (Glaser 2010, p. 103). In this study, I did not intend to develop formal theory. The aim was to provide a substantive account of diabetes experience within a particular context and in a particular time.

Kearney (2010) writes about how grounded theories are used to explain causation, highlighting the unique properties of grounded theories which allow this to happen. She refers to the way by which theories 'grasp' large volumes of data such that they cover a large spectrum of information. At the same time, grounded theory methods provide tools to achieve abstraction without completely sacrificing complexity. Hence, as Kearney (2010, p. 128) states:

> [A fully developed theory] does not simply posit that 'A' always leads to 'B,' but rather that the degree to which 'A' leads to 'B' and what that relationship looks like depends on a range of actors that influence 'A,' 'B' and the relationship between them.

A well-developed grounded theory will explain this complexity in the relationship between different phenomena. In this study, complex relationships have been found and will be discussed in the following chapters. For example, the relationship between family and self-management was amongst the most complex, being

influenced by the cultural context, by personal characteristics such as gender and by different interpretations of family interactions, such as whether these were perceived as helpful or intrusive to self-management. In summary, although various causal relationships emerged from the findings, none of these was straightforward and unconditional. This reflects the very complexity of human nature which GT methods addresses in the process of theorising.

3.7.2 Theoretical sensitivity

Glaser and Strauss (Glaser, 1967, p. 46), defined theoretical sensitivity as "an ability to have theoretical insight into [one's] area of research, combined with an ability to make something of [one's] insights." The inference of this was that researchers approach data with an open mind, so they can 'see' categories and concepts which might lead to theoretical insights. In their individual publications, Glaser and Strauss take a different stance on how the researcher may enhance theoretical sensitivity. For example, Glaser (1978, p. 3) wrote that:

> … the first step in gaining theoretical sensitivity is to enter the research setting with as few predetermined ideas as possible … the analyst is [then] able to remain sensitive to the data by being able to record events and detect happenings without first having them filtered through and squared with pre-existing hypotheses and biases.

This meant that the researcher should not immerse him/herself with reading the literature before data analysis. Glaser (1998, p. 164) does, however, suggest that the researcher reads literature in other disciplines to familiarise him/herself with the way "variables" are constructed in other fields of study.

In contrast to the idea presented by Glaser as mentioned above, Strauss and Corbin (1998) state that theoretical sensitivity comes from three places – literature, personal experience and professional experience. They argue that bringing one's own personal and professional experience to the field may be beneficial. However, they also point out that in theorising, one needs to use experience and knowledge to his/her advantage, rather than to obscure vision. This is because they also feel that

unless we are cautious, knowledge and experience can block our seeing what is significant in the data.

Because of the controversial way in which previous knowledge and experience may enhance yet at the same time block theoretical sensitivity, Bryant and Charmaz (2010b) refer to this concept as problematic. McLeod (2001) recommends addressing this issue through reflexivity, whereby the author reflects on his/her biases and assumptions. Acknowledging that my personal and professional background could serve to sensitise me to certain participant experiences, but in the process also block my view of others, I actively engaged in reflexivity from the very start. I made note of how these 'sensitising' experiences not only *could* but actually *did* influence my methods of collecting and analysing data. By becoming aware of this through reflexivity, I could rectify these problems immediately. More about this will be presented in the next chapter.

3.8   General features of Grounded Theory

3.8.1   Theoretical sampling and theoretical saturation

During data analysis, the researcher is involved in coding and developing categories through comparing data with data. As categories are refined and combined, theory will start to emerge. In relation to this process and according to Charmaz (2006, p. 96), theoretical sampling means "seeking and collecting pertinent data to elaborate and refine categories in [an] emerging theory." As the researcher compares data he/she starts making conjectures about the emerging categories and asks questions of the data. Further data collection is aimed at answering these questions and checking conjectures. In theoretical sampling, the researcher decides how to seek the best data for this purpose such as who to recruit for the next sample and what questions to ask of participants. The specific aim of this process is to develop properties of categories (properties are codes which explain or give meaning to categories). This is carried out until no new properties emerge. This way, categories become saturated with data and no further data collection is needed.

Much speculation has been made about the issue of theoretical saturation. Wiener (2010) states that saturation cannot be taken in its literal sense, as it is not possible to

achieve complete saturation. Strauss and Corbin (1998) also write that, in reality, there is always a potential for new properties to emerge. They suggest that the term should apply to situations where 'new' properties, which may be uncovered, do not add much to the explanation at that time. However, when and how researchers decide that additional data could not reveal any significant properties remains unclear. In fact, Dey (1999, p. 257) suggests using the term "theoretical sufficiency" as it better reflects how researchers make decisions about data collection.

In view of the controversy surrounding the issue of data saturation and in line with Dey's suggested term of 'theoretical sufficiency,' I decided to stop collecting data when I felt that these had sufficiently clarified the relationships between my main categories during the final stages of theorising. In fact, towards the end of my data collection, clarification of these relationships became the sole focus of my data collection and analysis. However, I still consider the term 'clarification' of relationships as more appropriate and realistic than 'saturation' of such relationships by data.

3.8.2 Constant comparison of data

This procedure is also a key feature in GT. It involves moving back and forth between the collection and analysis of data (Charmaz, 2006), such that these two procedures become a simultaneous and interactive process (Bluff, 2005). As the researcher questions data in emerging categories, he/she collects further data to answer these questions. New data is coded and compared with previous codes and emerging categories. This leads to recording new comparisons and refining categories (Charmaz, 2006). According to Bluff (2005), this process involves continually comparing words, codes and categories in order to identify similarities and differences in the data. Bluff (2005) explains how this intensive interaction with the data enables the researcher to better understand the phenomenon being studied.

3.8.3 Memo writing

Memos involve writing informal notes about reflections on the analytic process. In GT, analysis of raw data occurs through memo writing (Lempert, 2010). In fact, Charmaz (2006, p. 73) calls memos "informal analytic notes" and refers to them as a

way of "conversing" with oneself about the data. As stated by Glaser (1978), since writing memos is not as structured as in writing a formal document, there is more space for ideas to develop.

Much is written about the usefulness of writing memos. Generally, researchers use memo writing to keep track of what they think about the data and what coded data seem to "cluster together" (Stern, 2010, p. 119). They help the researcher move from initial descriptive notes to analytical thinking about emerging categories. Memos move researchers along this path by helping them capture the comparisons and connections they make. Finally, sorting memos helps the researcher to integrate theory (Stern, 2010). In Chapter 4, the role which memo writing played in my analysis will be discussed in more detail.

3.9   Adopting a constructivist approach to Grounded Theory

As stated by Urquhart (2013), GT can be influenced by different underlying epistemologies and it can be adopted by researchers who hold dissimilar assumptions about knowledge and how it can be obtained. This section will outline different worldviews of two main approaches to using GT: the 'positivist' (or objectivist) and the 'interpretivist' (or constructivist) approaches. Although the differences between these approaches may not be as straightforward as presented here, the aim of this section is to highlight the reason for my choice of 'constructivist' GT to guide my methods.

Upon being introduced to GT, I was immediately attracted to the constructivist approach because of its ontological and epistemological stance and the position it takes regarding the role of the researcher in developing theory. Charmaz (2006), who has written extensively about this approach, describes how constructivist GT may contrast in certain foundational assumptions with classic GT, as developed by Glaser and Strauss. Charmaz labels this latter approach as 'objectivist.'

The following quotation from Charmaz (2009, p. 129) embraces the main assumptions underpinning constructivist GT and the important standpoints it takes towards theory construction:

> [Constructivist Grounded Theory] assumes a relativist epistemology, sees knowledge as socially produced, acknowledges multiple standpoints of both the research participants and the grounded theorist, and takes a reflexive stance toward our actions, situations, and participants in the field setting and our analytic constructions of them.

According to the constructivist, a real world exists but is not separate from the viewers who may see it from different standpoints (Charmaz, 2009). The emphasis here is on multiple realities and the influence of subjectivity on people's views. This is in line with my assumptions about perceptions on diabetes support need, as described earlier in this chapter. This epistemological view may influence how developed theories may or may not be generalised. According to Bryant and Charmaz (2010a), amongst the constructivists, generalisations of a theory are partial and conditional. There is no intention of producing universal statements. These authors compare this to what they call the "generalising impulse" in classical GT where researchers focus on creating general abstract theories (Bryant & Charmaz, 2010a, p. 52). Also, on recognising diverse, local worlds, constructivist grounded theorists do not insist on finding a core category as in classical GT. Rather, it aims at understanding and theorising on the complexities of different worldviews and actions (Charmaz, 2009).

Charmaz (2009, p. 138) states that objectivist GT arises from positivism, and thus "assumes discovery of data in an external world by a neutral, but expert observer whose conceptualisations arise from the data." In contrast, in constructivist GT, data is co-constructed with participants (McCallin, 2009). Neither data nor theory is discovered. Rather, the researcher constructs grounded theories through his/her interactions with participants and research practices. This renders theorising a profoundly interactive procedure (Charmaz, 2009). As stated by Mills *et al.* (2006), the researcher adopts a position of mutuality between himself/herself and the participant, resulting in a co-construction of meaning.

As mentioned above, besides viewing data as being co-constructed, in constructivist GT, emphasis is placed on the interpretation and subjectivity of this data. As stated by Charmaz (2009), the researcher is involved in interpreting the studied phenomenon and not in producing an exact image of it. Likewise, data are

reconstructions of experience and not the original experience itself (Charmaz, 2003). Charmaz (2009) writes how the observations which researchers make and the views they form of them depend on their conditions, such as their perspectives, privileges, interactions and positions. Interpretations are therefore influenced by these factors, and so is the constructed theory. As Charmaz (2009) states, this calls for the need to take a reflexive stance throughout the research process. Here, the constructivists are involved in acknowledging their standpoints and studying how these may have influenced their analysis.

3.10   Conclusion

This chapter has addressed the way by which epistemological principles guided my research practice. The assumption that views regarding the need for support are subjective and multiple, led me to choose the interpretive paradigm which is associated with qualitative methods of research. These guided my general approach to investigation. Furthermore, I believed that views for self-management support are influenced by social interactions and I set out to explore the process by which this happens. This led me to choose constructive GT and the theory of Symbolic Interaction to guide my methods. These decisions were discussed in the light of controversies surrounding the related methods and the potential drawbacks of using a theoretical framework for research practice. The following chapter will elaborate on the methods I used to conduct my research.

Chapter 4

STUDY DESIGN AND METHODS

4.1   Introduction

This chapter describes the design of this study and discusses the methods used. The general approach to investigation was guided by my philosophical assumptions about the subject under study, as discussed in the previous chapter. This in turn influenced decisions regarding methods and materials used for data collection and analysis. Two different data collection methods were employed, namely focus groups and one-to-one interviews. These will be addressed separately in this chapter. For each method, the procedures which were followed for sampling and the recruitment of participants as well as for the actual collection of data, will be described and discussed. This is followed by a description of methods employed for data analysis. The chapter will also discuss ethical principles which were followed. Issues of reflexive practice and rigour are addressed towards the end of the chapter.

4.2   The study design

4.2.1   Overview

The study consisted of a single phase, qualitative design utilising in-depth exploratory focus groups and one-to-one interviews as a means of data collection. In-depth interviewing is synonymous with qualitative enquiry. Specific reasons for choosing this type of interviewing are explained below.

In-depth interviews allow participants to express their views about the subject under study, or about their 'subjective worlds' (Charmaz 2003, p. 312). Using open ended questions, active listening and probing techniques during the interview, enable the researcher to go beyond what is said in order to understand what is implied. Thus,

for example, it becomes possible to understand how incidents and cultural discourse are actually *interpreted* by participants. This is a central issue in Symbolic Interaction. Interviews also allow the researcher to actively interact with participants. In constructivist GT, such interaction is important as it allows a relationship to develop between the researcher and participants. This is required for co-construction of data. Strategies were envisaged to overcome any power imbalance between the participants and myself, which could impede the development of a functional relationship. More about this will be explained later.

Taylor (2005, p. 40) cautions researchers about a particular limitation with in-depth interviewing. She refers to how participants' ability to construct and reconstruct their daily lives and experiences during interviews, is influenced by the extent to which they can "articulate, reflect on and recall experiences and accompanying emotions". This was considered particularly relevant to one-to-one interviews which were aimed at studying these experiences in-depth. The following sections will discuss the rationale behind combining focus groups and interviews, and the methods used for this approach.

4.2.2   Rationale for combining focus groups and one-to-one interviews

The decision to use both types of interview methods was mainly driven by unique data quality which can be obtained from each approach. As highlighted by Farquhar (1999), interviews held in the 'public' context of the focus groups may elicit data which is different from those held in the 'private' context of the individual interview. Thus, one method of data collection will complement the other.

The complementary role of the focus group and one-to-one interview is also seen in the way they address depth versus breadth in the understanding of phenomena (Krueger, 1994). In a group discussion, a broader range of ideas are brought to the fore. This was important in this study as it held a broad scope, aiming to identify perceived need across multiple dimensions. It is understood, however, that a focus group approach is likely to miss out on detailed understanding of individual experiences and perceptions (*ibid*). In this study, the broad understanding of support need achieved in the focus groups, directed the in-depth enquiry used in the one-to-

one interviews.   In this respect, one-to-one interviews were aimed to achieve completion of data, through allowing further exploration of phenomena.

4.2.3   Procedures used for combining focus groups and one-to-one interviews

I combined focus groups and one-to-one interviews in a single-phase study which commenced with focus groups. As data were analysed and categories started to emerge, I began to conduct one-to-one interviews with individuals specifically chosen from the previous focus groups. I went back to these individuals with the intention to explore further and delve deeper into some of the emergent categories. One-to-one interviews were conducted in between focus groups, helping to elaborate on data collected from these groups. This is referred to as an integrated use of both methods (Lambert & Loiselle, 2008).

Throughout the data collection period, focus groups helped to determine the most pertinent questions to be further explored during an individual interview. They also helped to choose the individual/s from the focus group who could best elaborate on specific topic areas during a one-to-one interview. This formed part of theoretical sampling procedures. Combined data analysis of the focus group and the individual interview/s then guided sampling and questioning for the following focus group. This iterative process, characterised by going back and forth with regard to data gathering and analysis of different forms of data, was repeated throughout the data collection period. According to Lambert and Loiselle (2008), this process helps to further conceptualise the phenomenon under study.

Shortly after commencing data collection, I decided that besides choosing individuals from previous focus groups for one-to-one interviews, I would *also* start selecting new individuals who would not have participated in a group. There were some advantages associated with this method. It was assumed that focus group discussions would influence data obtained during one-to-one interviews, from participants who would have participated in these discussions. It was thus necessary to also get fresh, in-depth insights from individuals who were new to the study. Furthermore, choosing focus group participants was associated with problems

inherent in interviewing individuals who already knew me. Spradley (1979, p. 50) suggests against choosing individuals with whom the researcher has an established relationship. This is so that participants are able to assume that the interviewer is "naively ignorant" about their experience in the subject area. Otherwise, they might avoid discussing issues which they would think the researcher already knows about. Hence, a mixture of individuals participated in one-to-one interviews, including both those who were new to the study and those previously involved in the research.

The following sections will explain and discuss procedures carried out in relation to focus groups and one-to-one interviews. Since these procedures varied between these two data collection methods, such methods will be addressed in separate sections.

4.3   Conducting focus groups

This section will outline considerations made in relation to choosing focus groups as a method for data collection. It will also explain all procedures involved in the use of this method, including sampling, participant recruitment, organisation of focus groups and running these groups.

Focus groups are specifically aimed to derive data from group interaction (Kitzinger, 2005). This factor associates focus group data with various advantages and drawbacks compared to data derived from one-to-one interviews, as will be explained below.

4.3.1   Advantages of collecting data through focus groups

A substantial amount of literature is available which tackles the specific value of focus group data in research. Due to the way data is derived from discussions between members of the group, focus groups are considered to possess the capacity to become more than the sum of their participants, achieving a synergy that cannot result from adding the contribution of each member alone (Krueger, 1994). The following sections discuss the value of focus group data.

4.3.1.1   Value of focus groups derived from the focus group setting

In a focus group setting, questions are presented to the group as opposed to the individuals within it. Thus, individual members do not feel that they should respond to each question. Rather, as Stewart *et al.* (2007) point out, they speak only when the subject relates to their interests or experiences. According to these authors, in such a situation, the individuals' responses become more spontaneous and unconventional and hence better reflect their position in relation to the subject area.

Most central to the focus group setting are the group dynamics that develop. These may elicit individuals' contributions, which may otherwise remain untapped. Farquhar (1999) explains how within a group, certain members may break the ice for shyer participants who may initially be hesitant to contribute their thoughts. On a similar note, Stewart *et al.* (2007) refer to how individuals within the group may decide to speak up when they realise that their feelings or experience are not so different from those of the other members.

4.3.1.2   Value of focus groups derived from exchanging ideas

As stated by Kitzinger (1994), during group meetings, ideas and perspectives may be both stimulated and clarified between individuals in ways that would be less accessible during one-to-one interviews. Stewart *et al.* (2007, p. 46) label this phenomenon as 'snowballing,' referring to how a comment made by one participant often prompts a chain of responses from other group members. In line with these arguments, Frey and Fontana (1993) refer to how, in addition to the respondent-interviewer relationship, the relations which develop among group members can encourage elaboration and expression. This stimulating environment was deemed important to this study as it would encourage participants to explore diabetes care issues of importance to them, helping them to identify and pursue their own priorities.

Kitzinger (2006) also refers to how group discussions have been found to generate more critical comments than interviews. As the author asserts, when the aim of research is to improve service, focus groups thus become the ideal method for

facilitating criticism and exploring possible solutions. This further highlights the relevance of focus groups to the purpose of this study.

4.3.1.3   Value of focus groups derived from observing group interaction

Pertinent to this study is the way focus groups allow the use of everyday forms of communication between participants. According to Kitzinger (2005) this informal talk between participants, including the use of jokes, personal accounts or loose word connections, may highlight cultural and subcultural values. Kitzinger (1994) writes how such forms of communication may reveal aspects of understanding which may not emerge during one-to-one interviews. It was noted, for example, that participants in this study, often joked about their non-adherence to diet during social occasions, such as wedding receptions, dissociating this experience from shame and depicting it as a 'normal' occurrence in self-management. This observation contributed to understanding the cultural role of food in the lives of participants, as will be discussed later.

4.3.2   Weaknesses of focus groups

Whilst the above sections have referred to how group dynamics may encourage expression of ideas and the voicing of opinions by more reserved individuals, the actual downside of focus group is mostly related to how the same dynamics may, at times, reverse this situation. Kitzinger (2005) refers to how individuals may be silenced by vocal people in the group who tend to dominate the discussion. Also, as Kitzinger (1994) points out, the articulation of group norms may inhibit individuals from expressing opinions which may be different from these norms. This way, the group creates pressure to conformity (Knodel, 1993). Careful moderation is required to minimise these factors. Moreover, as stated by Kitzinger (1994), group dynamics may be so powerful as to make individuals drastically change their opinions in response to arguments put forward by other group members. These factors may affect the actual validity of the data obtained.

In the light of the problem mentioned above, during data analysis, I reflected upon the extent by which the data I had obtained could have been influenced by group

norms. This sometimes involved scrolling through the script to try and establish the likelihood that what individuals had stated at particular points, might have been influenced by the way the subject was being discussed. In fact, analysis of complex data presents yet another challenge of focus group research. Krueger (1994) explains how the strength of focus group data is only achieved if comments are not lifted out of context during analysis. He points to the limitations imposed by ignoring the sequence by which topics are addressed and emphasises on the need to examine the way thoughts are developed during the discussion.

Finally, Stewart *et al.* (2007) refer to limitations associated with generalising focus group data, considering how persons who are ready to travel to participate in a focus group may be different from other members of the target population. In this study, incentives were planned to minimise this affect, although it was recognised that this could not have been excluded altogether.

4.3.3   Sampling procedures for focus groups

The study (target) population from which participants were selected consisted of adults with Type 2 diabetes who made use of public health services for their follow-up care. Purposive sampling was used in the beginning of data collection. This means choosing participants who reflect the range within the total study population (Kitzinger, 2006) and who have knowledge about the subject being studied (Bluff, 2005). Individuals were chosen to represent a range in relation to important characteristics which could influence self-management, such as age, gender, level of education, duration of diabetes, type of treatment received, occupational status and source of follow-up care. A little more than half of the sample was chosen from amongst patients who attended the Diabetes and Endocrinology Unit, which is an outpatients clinic at the public general hospital, and the rest of the sample was chosen from those attending diabetes clinics within community-based health centres. The latter clinics are dispersed across different geographical regions in Malta. Patients were selected from four of these clinics, making sure that individuals from both the north and south of the island were included. It was important to choose participants from both the hospital and community clinics, as those who are referred to the latter, are usually the ones whose diabetes is well-controlled. Individuals with

poor diabetes control are followed up at the hospital clinic as described in Section 2.5.3.1. The intention was to include both type of patients in the sample.

An effort was made to also choose participants who only used private follow-up care. A number of doctors and specialists who held private clinics were approached to help with the recruitment of such patients. It is important to note that all those approached mentioned that their private patients also made use of the public diabetes health services. The reasons given were varied and included issues involving free medications and free non-routine investigations. These medications/investigations have to be ordered by health professionals working in the public sector, so all individuals with diabetes are keen to make use of the services offered by the public health service. Hence, it was then decided to only carry out sampling and recruitment from public health clinics, as this would automatically also include those who made use of private care. Inclusion criteria for this study were the following:

- Having Type 2 diabetes for at least one year;
- Being between 18 and 75 years of age;
- Being free from conditions which may limit participation in a focus group discussion, such as hearing and speech problems.

Individuals older than 75 years were not included as it was likely that comorbidity, including conditions unrelated to diabetes, such as arthritis, would significantly influence perceived support needs amongst this cohort. Including only those individuals who have had Type 2 diabetes for at least one year ensured that all participants would have enough experience with living with diabetes to be able to identify support needs arising at the time of diagnosis and later.

In line with a GT approach, theoretical sampling was used once data analysis commenced and theory began to emerge. This sampling technique seeks pertinent data to develop emerging theory (Charmaz, 2006). This technique gave me ideas of whom to choose for subsequent groups in order to gather data, which in turn would contribute further to theory development.

4.3.4 Recruitment of participants for focus groups

Health professionals working with patients in the different public health diabetes clinics were asked to help select patients as they attended for their follow-up appointments. This may have influenced the type of patients chosen since professionals could have been inclined to choose patients whom they liked or with whom they felt most comfortable to communicate. During recruitment important demographic and clinical information was collected for each participant, as will be described below. Participant recruitment for each focus group started about four weeks prior to the focus group and took about ten days to be completed. In order to be able to address any problems or queries which might arise during the recruitment process, I made sure that I was present during the clinic times when recruitment took place. The recruitment procedure that was adopted is outlined below. An English version of information sheets and consent forms that were used are included in the Appendices as indicated. A font size thirteen was used in written correspondence with participants in view of possible visual problems.

1. During follow-up visits, nurses who worked at diabetes clinics normally saw patients and checked their parameters before these patients were seen by the doctor in another room within the same clinic. The selection process took place during these nurse-patient encounters.

2. Nurses were asked to identify eligible individuals based on the inclusion criteria mentioned above. To do this, they asked their patients questions and while communicating with them, they checked for any communication problems which they might have had. To check on type of diabetes, nurses were asked to apply criteria used in other studies, such as the large multi-centre DAWN 2 study (Nicolucci *et al.,* 2013). According to these criteria, patients with Type 1 diabetes would be those who were diagnosed before the age of thirty, who started insulin treatment at diagnosis, and who continued to use insulin treatment. Nurses were asked to inform eligible individuals about the study and to give them the patient information sheet to read while they waited to see the doctor (Appendix 2).

3. Patients were instructed to verbally inform the nurse if, after reading the information sheet, they were interested to participate. The nurse then:

      a.   Asked these patients to sign a consent form, giving permission to the nurse to give their personal details to me, including their contact number (Appendix 3).

      b.   Asked these patients a few questions to obtain further personal information needed for the study. This information was about personal characteristics, such as occupational status and type of treatment received. The nurse wrote this information on a form purposely provided by myself (Appendix 4). This form was then handed to me. When nurses were very busy, I would obtain this information from the patients myself. This always occurred after having received a written consent from the patients, that I could be given access to this information.

4.   In the case of those eligible individuals who were illiterate, the nurses were asked to read them the information letter and to give them a brief explanation about the study. They were also asked to outline the participative role that they would be required to take on. When an individual expressed an interest to participate, the nurse read out the consent form so as to obtain their permission to give me their personal details.

5.   A few days after recruitment, I called each individual to confirm their intention to participate. I wanted to allow them more time to read the information sheet and to reconfirm their availability on the particular date of their focus group. During this telephone call, I was also able to answer any queries which they might have had.

6.   After the call, I sent a brief letter to those who had confirmed their participation. In this letter, I thanked them for accepting this invitation and included the scheduled date, time and venue for the focus group (Appendix 5). I enclosed a parking permit and a map indicating the area for free parking.

7.   One day before it was scheduled to take place, I reminded the participants of the focus group. I sent a reminder message to those who had provided me with their mobile number and called the others on the telephone.

4.3.5 Organisation of focus groups

4.3.5.1 Composition of groups

As stated by Stewart *et al.* (2007), care must be given to the composition of each group because the interaction between its members will determine the quality of the

discussion and perhaps even its direction. According to Knodel (1993), grouping strategies should be based on two major considerations:

- How individuals' characteristics may influence the topic under investigation (in this study this would be the need for self-management support).

- How individuals' characteristics may influence frank group discussion.

Considering the above suggestion, I decided to mix different characteristics (such as gender, age group, type of diabetes treatment received) within each group rather than separate groups in terms of such characteristics. In other words, the focus would be on heterogeneity within groups. Should problems with group interactions be identified, I would then reconsider my method. The main reasons for this decision were the following:

1. There are too many different characteristics which could influence support need and group discussion and it was impossible, with the limited resources available to subdivide groups by these various factors.

2. As Krueger (1994) suggests, although some mixes of participants do not work well because of limited understanding of other lifestyles and situations, this may not be an issue when the topic under study clearly cuts across these factors. It was believed that this would apply to this study. Despite the variety of individuals in the group, the commonality of sharing the experience of living with diabetes may be powerful enough to render the group sufficiently homogenous to enhance participation from all.

After having conducted five focus groups I realised, both through moderating the groups and analysing the data, that participation from males and females during the focus groups was unequal. Males were participating more than females. In fact, using NVivo qualitative data analysis software to make estimations, I found that the average percentage coverage of focus group discussions *per person* was significantly higher in males than in females. On average, the contribution from a male participant in a focus group discussion was approximately 50% greater than that of a female. This imbalance was exacerbated by the fact that males slightly outnumbered females in the first five focus groups (Appendix 19). In order to make up for this

lack of female generated data, I decided to recruit only females for the sixth and last focus group. This would also address any inhibitions which female participants might have had to vocalise their opinions in the presence of their male counterparts. In fact, it was noted that female participants were more relaxed during this group and tended to discuss emotional issues more freely than in the previous groups.

4.3.5.2   Venue for meetings

Focus group meetings took place in a lecture room at the diabetes outpatients clinic at the general public hospital in Malta (Mater Dei Hospital). One important advantage with using this venue was that there are direct bus routes to Mater Dei Hospital from various localities in the country, thus facilitating transport. The main disadvantage with using a department within a public hospital was that participants might have associated this with the study being carried out by a governmental agency. This might have impacted on their responses. Meetings were held early in the evening to increase the likelihood that individuals who were gainfully occupied would be able to attend. This also ensured that the venue would be quiet as there would be no patient visits at this time.

The room was organised to create an informal and relaxed environment. Seating was comfortable and arranged in a circle. As illustrated by Stewart *et al.* (2007) this seating arrangement makes it easier for group members to see one another and to maintain eye contact which facilitates discussion.

4.3.5.3   Number and size of groups

In GT, it is suggested that data collection will stop when categories are saturated with data (Charmaz, 2006). As discussed in the previous chapter, in seeking to reach data saturation, I continued collecting data until I felt that the relationships between my main categories were sufficiently developed. Therefore, as such, the number of focus groups was not tightly predetermined.

With regards to size of groups, Kitzinger (2005) suggests smaller groups (of around six to nine individuals) when group members have a lot of ideas/experience to share,

as was assumed to be the case in this study. I opted for over recruitment to make up for those who failed to turn up on the appointed day. Thus, ten individuals were recruited for the first group and they were all present on the day. During this focus group, I observed that participants did not have enough time to express their opinions and I felt that the number was simply too big. Consequently, for subsequent groups only eight participants were originally recruited. However, on a number of occasions one or more of the recruited participants called to opt out of the study a few days prior to the scheduled meeting. There were eight of these instances in all. In these occasions, and when there was enough time, I recruited other participants to replace the ones who had opted out. Ultimately, overall only a few of the recruited participants failed to turn up on the day, such that the number of participants in the focus group was never less than seven.

4.3.5.4   Running the groups

I acted as the moderator of the focus groups. One observer accompanied me to take notes during discussions, particularly of significant non-verbal communication (Krueger, 1998). These notes were used to supplement the audio taped information. The observer also took notes of what was being discussed so as to come up with a summary at the end of the focus group, which she would read out to participants. Another individual accompanied me in order to write the sequence in which participants spoke, making note of the first few words which each participant said in each of his/her contributions. This account was given to the transcriber to help with identifying who said what during transcriptions. These assistant moderators also helped in the general running of the group activity, but did not participate in the discussions. It is acknowledged that the presence of three researchers and the fact that the interview was recorded could have had an inhibiting effect on individuals' participation.

Participants' willingness to disclose could also have been influenced by the way I managed my identity. Consequently, I was careful how to dress for the focus groups, dress being considered as another symbol, open for interpretation during interaction. I made sure that my appearance would not communicate power differences between the participants and myself. Both my assistants and I dressed in

a smart yet unsophisticated manner. There were other aspects of my identity which were likely to influence participation. This will be discussed in detail in another chapter.

As individuals were gathering for the focus group, some refreshments were given including a drink and a snack. The aim was to allow some time for individuals to get to know one another and to create a more relaxed environment. At the outset of the meeting, before the discussion was initiated, I gave a brief introduction. I thanked participants for attending and reminded them of the purpose of the study and that the discussion would be recorded. Some ground rules were set, including those related to confidentiality. Participants were also reminded that they could still choose to withdraw from the study. They were then asked to sign a consent form, indicating their willingness to participate. Consent forms were collected and each participant was given a copy of the form (Appendix 6).

Before commencing the discussion, participants were asked to introduce themselves. This was important as a warming up activity as well as to enable the transcriber to connect participants to their voice during transcription. Participants were given the option not to give their real names during the introduction. This was used as a means of reassurance since confidentiality amongst members in the group could not be guaranteed. I informed participants of this option when I called them during the recruitment phase. For those who preferred not to disclose their names (there was only one such participant), we decided upon a fictitious name, which would be used during the focus group. I made a note of the change in name. During focus groups, participants wore a tag with their name (or the fictitious one they chose to use) so that everyone knew how to address each other.

As Krueger (1994) points out, participating in a focus group requires time and effort. Therefore, incentives are needed to act as a motivator to attend the session. At the end of the focus group discussion, each participant was given a diabetes recipe book to act as such an incentive (recipe books are very popular in Malta and I bought different books from which participants could choose; all books had nutritional information about each recipe). Upon ending the focus group, I also informed participants that I might need to interview members of the group on a one-to-one

basis at a later stage of the study. Participants were informed that they would again be free to decline from participating should they be approached for this purpose.

4.3.5.5 *Moderating the discussion*

A recommendation made by Krueger (1998) was considered central to enhancing success in the focus group. This is about the moderator truly believing that participants have valuable wisdom to share, no matter what personal packages they bring with them. I took this standpoint. I did my utmost to listen attentively and with sensitivity to what each participant had to say. On the other hand, as Krueger (1998) further recommends, I refrained from engaging in discussions by sharing my views and my values, thereby crossing the line between the role of moderator and participant. This would risk inhibiting disclosure of alternative views from participants.

The initial brief introduction (referred to in the section above) served to try and create a non-threatening environment. I emphasised the fact that there were no right or wrong answers to the questions that were asked, that all individuals' opinions were important and that everyone had valid contributions to make. This would minimise any power difference perceived by participants. Efforts towards maintaining such a non-threatening environment were maintained throughout the session.

During the discussion, all members of the group were encouraged to speak. This was occasionally achieved by asking a direct question to any member of the group who seemed to be reluctant to speak. The use of this measure was kept to a minimum because spontaneous responses were considered to be of greater value. Also, verbal encouragement was given when an otherwise reluctant individual offered his/her opinion. As suggested by Stewart *et al.* (2007) effort was made to take note of facial expressions or gestures which could indicate that a person was about to speak, or that he/she was disagreeing or feeling puzzled by what was being said. These measures were central to keeping the participation of members balanced.

The use of probes was executed with caution. As stated by Krueger (1998), while eliciting information, probes should not suggest a specific response or make the respondent assume a defensive position. Some probes were planned and included in the interview guide (which will be described later). Others were used as the need arose. I tried to refrain from talking too much, asking too many questions, or moving too quickly from one topic to another.

Sometimes it was necessary to deal with what Stewart *et al.* (2007, p. 99) refer to as 'self-appointed experts.' These individuals tend to dominate the discussion and may intimidate others. Stewart *et al.* (2007) and Krueger (1998) mention various ways of dealing with such situations and these include avoiding eye contact with them, and purposely failing to recognise that they wanted to speak. When this did not work, I tactfully stopped them, asking for opinions from the others on the subject. Effectively dealing with these individuals was considered important in ensuring equal participation and promoting cohesiveness of the group. Making sure that everyone had an opportunity to speak *and* be listened to was the most challenging aspect of moderation. Many participants were extremely eager to voice their opinions and concerns. Also, it is part of Maltese culture to talk loudly and to speak over one another.

Finally, I made an effort not to influence the data, such as through reinforcing points of view that were consistent with mine. Feedback on any instances where my ideas could have influenced the data was obtained during debriefing sessions which I carried out immediately after each focus group with the assistant moderators. As suggested by Krueger (1994, 1998), these debriefing sessions were also used to capture first impressions of the focus group, identify questions which did not seem to work and changes which could be carried out in the interview guide.

4.3.6   Reflecting on the focus group

I found organising, preparing for and running focus groups a very demanding exercise. I felt exhausted after each group. However, I realised that to reap the benefits of this exercise, I needed to reflect deeply upon all that had happened. As mentioned above, reflections started immediately after each focus group through the

debriefing session I had with the assistant moderators. The day after the focus group, I would write all my reflections on the focus group. Besides reflecting on how I could have influenced my data, I also made note of things such as the atmosphere between the members of the group, the group dynamics that had occurred and the general impact that these could have had on the data. I wrote about any particular incidences that were important to note and about my moderating behaviour

4.3.7   Developing the interview guide

The interview was planned to be of a semi-structured format. As highlighted by Stewart *et al.* (2007), with focus groups, it is important to strike a balance between unstructured and structured interviews. Due to my lack of experience in qualitative interviewing, upon preparing my interview guide, I chose to write the main questions in advance (Appendix 7). Attention was placed on the logical and sequential flow of questions. A sequence suggested by Krueger (1994) was adhered to. A first opening, round robin question was asked to elicit factual information and encourage everyone in the group to talk from the very start of the session. The next question, which was asked to the whole group, was broad. Participants were asked to talk about their experience of diabetes. This would help them reflect on their connection to the subject area. This was followed by what Krueger calls 'transition' questions. These move the conversation into the key question that drives the study. Transitional questions asked participants to reflect and talk about factors which hindered or helped their self-management. This discussion would logically lead to the key question which asked participants about what they thought would support them to carry out self-management. Ending questions were planned to bring closure to the discussion, and help group members to reflect on what had been discussed. Although this sequence of questions was planned beforehand, it was sometimes changed during the interview, letting the flow of conversation run as naturally as possible.

All questions were open ended, one-dimensional and phrased in simple Maltese language, avoiding jargon. Open ended questions are known to allow participants to express their views while focusing on what they feel is most important (Stewart *et*

al., 2007). Questions were structured so as to sound conversational and were asked conversationally during the focus group.

Once developed, the interview guide was reviewed by experts, including my supervisors as well as a local diabetes specialist nurse who was very familiar with the type of people who would participate in this study. It was also reviewed by an individual with diabetes. Eventually, amendments to the interview guide were implemented according to the need emerging from previous data analysis. This is in line with theoretical sampling and constant comparative analysis. Nonetheless, some ground rules in designing the questions, as mentioned above, were consistently adhered to.

4.4 Conducting one-to-one interviews

As mentioned earlier in this chapter, the main rationale for conducting one-to-one interviews was to further explore important themes emerging during analysis of focus group data. Individuals chosen for these interviews were either new to the study or they would have previously participated in a focus group. This section will highlight the main methodological procedures involved with one-to-one interviews, including sampling and recruitment of participants, conducting the interviews and constructing the interview guide.

4.4.1 Sampling

A combination of purposive and theoretical sampling was used to select participants for one-to-one interviews. From amongst those who had participated in focus groups, I chose individuals who could best provide data required to develop emerging categories. This formed part of theoretical sampling. For example, as the issue of stigma emerged during analysis, I chose an individual from a previous focus group who seemed to have been influenced by this social attitude. During the one-to-one interview, we elaborated on this subject. On the other hand, individuals who were new to the study were mostly selected on the basis of their demographic characteristics, as part of purposive sampling. In fact, this mainly involved young individuals who were hard to come by in the short period of time dedicated to

selecting participants for focus groups. This is because Type 2 diabetes is more common amongst individuals of a mature age. When recruiting for focus groups, I would have a set date, so recruitment phase had to be short. Conversely, recruitment period for one-to-one interviews was not limited by time, so it was easier to find young participants for these interviews.

4.4.2   Recruitment

Once the persons from previous focus groups were chosen to participate in one-to-one interviews, they were sent a patient information letter, informing them of the further participation which was being requested of them (Appendix 8). A few days later, the nurse working at the clinic from where these participants had been initially recruited, called them to check whether they would be interested to participate. If confirmation in the affirmative was received, the nurse asked whether the participant would allow the researcher to make contact by telephone. Once this permission was granted, I called the participant to make arrangements for the interview. A venue and date, which were most convenient for the participant, were chosen. Details were then sent by post. Each individual was contacted a day before the interview to confirm his/her attendance.

In order to recruit individuals who were new to the study, the same recruitment procedures used for focus group participants was adopted (see Section 4.3.4). I used the same inclusion criteria and participants were chosen by health professionals working at diabetes clinics, who then referred these participants to me. Interviews with these participants were also conducted on a date and at a venue most convenient for them.

4.4.3   Conducting the interviews

One-to-one interviews were conducted in individuals' homes, at their place of work, or at the Faculty of Health Sciences where I work, which is situated in the same building of Mater Dei Hospital. Before starting the interview, participants were asked to sign a consent form, confirming willingness to participate (Appendix 9). A light snack and coffee were offered during the interview, when these were conducted

at my place of work. Recipe books were again offered as a token (different recipe books were given to those having attended the focus group), together with educational leaflets on diabetes.

Techniques which encourage participants to share their points of view were used throughout these interviews. These techniques were similar to those used in the focus groups and included measures which promote a non-threatening and informal environment and which reduce perceived power difference between the researcher and interviewee. They also included proper use of questioning, probing, clarification techniques and empathy. These were central to building or maintaining a relationship with the participant.

4.4.4   Constructing the interview guide

As with focus groups, one-to-one interviews adopted a semi-structured format. Thus, as suggested by Britten (2006), the interview consisted of open ended questions which defined the area to be explored, whilst maintaining a loose structure. This was needed not to inhibit the process of discovering what was important to the participant. On the other hand, the lightly structured format allowed me to focus on the key issues that were emerging in the analysis of previously collected data. The same principles for constructing questions for focus group interviews were used for one-to-one interviews (see Section 4.3.7).

4.5   Data Analysis

4.5.1   Introduction and overview of the analytic process

As discussed in the previous chapter, I used the writings of Charmaz about constructive GT to guide many aspects of my methods. However, when it came to data analysis, I found some of Charmaz's guidelines unhelpful. For example, I could not agree with Charmaz's (2006) principle of focused coding. This requires that the analyst chooses amongst initial codes to determine which of these are most meaningful. These codes are then raised to a higher level of abstraction and subsequently, developed into theoretical codes/categories. This involves the need to

make decisions about codes at a very early stage in the analysis. Disagreeing with this principle, I decided to use an eclectic approach towards data analysis. I chose analytic methods suggested by different authors of GT, which best suited my needs and with which I felt most comfortable. My choices were consistently aimed at maintaining rigour in my data analysis, remaining true to the data while allowing an element of creativity in identifying processes and conceptualising my data.

The central features in my data analysis were constant comparison of data, organising these into categories and developing these categories by elaborating their properties with incoming data. Finding associations between categories finally led to integration of theory. The next sections will explicate how these processes were carried out, simultaneously with theoretical sampling. Other aspects of data analysis will be addressed, including transcribing, choosing the language to work with and using software for computer assisted analysis.

4.5.2   Transcribing

Interviews were transcribed verbatim in the original Maltese language. As stated by Charmaz (2006), using full interview transcriptions for coding, gives the researcher ideas and understandings which could be otherwise missed. I asked a Maltese transcriber to carry out transcriptions. However, I listened to the recordings repeatedly while checking out the text after each transcription. Whilst helping to bring data 'alive' by refreshing my memories of the interviews, this enabled me to study the text in great detail. During this process, I considered the notes that had been taken by the assistant moderator during the focus groups and by myself during the one-to-one interviews. I also made sure that factors such as pauses, tone of voice and laughter were noted.

4.5.3   Translation of transcripts

Perhaps one of the most difficult decisions made regarding data analysis was whether to translate the Maltese transcripts into English before coding, or whether to code directly from the Maltese transcript. My aim was to ensure methodological rigour while remaining culturally sensitive to my study population. My ultimate

decision was not to translate the text but to code directly from Maltese transcripts. Codes, at all levels and all memos would be written in English. The rationale for this decision was to enhance accurate and holistic analysis, but practicalities associated with this approach were also considered. These are discussed below.

4.5.3.1   *Promoting accurate and holistic analysis*

Minichiello (1990) states that keeping close to the original text during analysis is essential for ensuring rigour. On a similar note, Vallance and Lee (2005) write about how using transcripts in the original language enhances trustworthiness as it facilitates accurate analysis. As these authors point out, preserving meaning during translation is often very difficult as figures of speech such as metaphors, idioms and similes are so very different across languages. Having to translate these figures of speech may mean losing the power of their meaning and possibly the context in which they are stated. Vallance and Lee (2005) also write how transcribing and coding from the original language enables the researcher to examine nuances of the text. This is important, for example, when similar ideas are expressed differently amongst participants, sometimes highlighting issues of personality or small but meaningful differences in the ideas being expressed. These subtle differences may be ironed out during translation of texts.

Vallance and Lee (2005) also state that coding from the original language ensures rigour, as it enhances holistic analysis. The researcher can better appreciate the cultural elements in a conversation when analysing in the original language. A typical example is understanding how humour or cultural norms are communicated in a conversation. This is supported by Spradley (1979, p.17) who highlights the connection between culture and language, referring to language as a 'tool for constructing cultural reality.' Thus, it was felt that understanding the cultural influence on diabetes self-management necessitated the scrutiny of Maltese transcripts.

4.5.3.2   *Practical issues*

Coding in English from a Maltese transcript was also considered in the light of practical issues. For example, the computer assisted qualitative data analysis software (CAQDAS), NVivo, which I planned to use, can assist research done in a language other than English. The fact that Maltese language employs the letters of the Roman alphabet would facilitate this process. Furthermore, to the Maltese population, English is the second national language and is the official language which is used in higher educational settings. As with most local academics, I have a very good working knowledge of both Maltese and English. Since I regularly use English in my work and in my daily life, I am used to switching from one language to another, and this skill was deemed essential when coding straight to English from Maltese transcripts.

Whilst the above arguments are in favour of coding from text in the original language, this approach limited my ability to discuss coding with my supervisors, both of whom were English. This meant that they could not read the full accounts to verify that the analysis conformed with procedural norms. This also meant that my analysis was less open to critique and discussion than I would have preferred. Nevertheless, I used other methods to double-check my coding, as will be explained later in this chapter.

4.5.3.3   *Translation of excerpts*

Although it was decided not to translate the whole transcript, translation was still required for *in vivo* codes and excerpts. I carried out these translations myself. As stated by Jootun *et al.* (2009), in order to come up with accurate and valid translations, the translator needs to be fully engaged with meanings and discourses. Being actively involved in the focus groups and having checked all transcribed materials, helped me to be well-engaged with the conversations and allowed me to be in the best position to understand intended meanings in the text. My aim was not to translate 'literally' but to obtain conceptual equivalence during translation. This involves not only the translation of words but of the meaning or intent of the words (Allen, 2000). When using this approach, checking or validating accurate translation by carrying out forward and back translation (Brislin, 1970) has been found to be

unsuitable (King *et al.*, 2011). I decided to check these translations with a professional translator and any disagreements between us were discussed.

4.5.4   Using computer assisted analysis

Computer assisted qualitative data analysis software (CAQDAS) is known to help researchers manage their data and it was for this reason that I chose to use NVivo for my data analysis, knowing that I would have large volumes of data to work through. In general, NVivo was found helpful due to the way it organises and displays data and because it renders all elements of data analysis easily accessible, just a click away. All these analytic elements, such as transcripts, codes, excerpts and memos, are effectively linked within the programme, such that during my analysis, I could move swiftly from one element to the other as I strove to compare, interpret and code the data. This also facilitated the iterative process of data gathering and analysis, in relation to which I had to constantly move back and forth between 'new' and 'old' data.

There were various specific ways by which CAQDAS enhanced efficiency and rigour in my analysis and some examples are briefly outlined below. Key features used are written in bold font.

1. Some properties of categories were developed during later stages of analysis. Using the **text search facility**, I could search all previous interviews (at one go) and use an advanced search facility to see whether in the past, I had missed any opportunities to code for these properties.

2. NVivo was found particularly helpful for analysing focus group data. For example, through opening **participant nodes**, it allowed me to view, in a single display, all excerpts of a single participant within a specific focus group, as well as all the codes developed from these excerpts. This enabled me to obtain a profile of each participant's diabetes experience and his/her contributions in relation to my developing theory. Amongst other analytic advantages, this facilitated the selection of focus group participants for one-to-one interviews, as part of theoretical sampling.

3. Using **open reference source**, I could move swiftly from codes to their textual origin during coding, to examine and re-examine the

context from which codes had been extracted. This ensured that codes are not removed from context during analysis.

4. Through the way it can organise and display data, NVivo helped me identify patterns in my data which were important for theory development. For example, I could visualise the differences by which females and males referred to family support. This was enabled by **matrix queries** which can effectively compare groups of data and link them with participants' demographic information.

4.5.5   Coding

Coding involves finding and labelling meaningful units of data. According to Glaser and Holton (2004) coding is a means for conceptualising data and as such, Charmaz (2014, p. 113) refers to coding as the "pivotal link between collecting data and developing an emergent theory." Grounded theorists describe different stages of coding which involve escalating levels of conceptual abstraction of data. As Birks and Mills (2011, p. 95) point out, although coding happens in different stages, the "recursive nature" of GT requires that throughout their study, researchers move across different stages, as they simultaneously collect and analyse data. Grounded theorists use different terminology to describe these coding stages. Since I have adopted coding practices proposed by different authors of GT, I will use my own terminology for naming the various coding stages I employed. These are described below.

4.5.5.1   First level coding

First level coding represents the initial stages of the coding process. Glaser (1978) writes how initial coding fractures or opens up the data in the process of comparing incidents within it. I chose to closely examine my data by coding short segments of it. As Birks and Mills (2011, p. 96) point out, this concentrated approach "avoids the risk of missing important concepts that may only be identified after prolonged and intense engagement with the data." I chose to code all segments which were related to participants' experience of self-management and which could somehow contribute to answering my research questions. These criteria were used to determine what constituted meaningful units of data. When labelling the code, I thought hard about the context in which things were said, often drifting up and down the text in the

process, making sure that nothing was lifted out of context. I made sure that the words or phrases which best convey the intended meaning were used in the code. When the choice of words of participants was very particular, these were either carefully translated or coded *in vivo*. In the latter instance, the Maltese words were left in the code, together with an English translation.

I tried to keep the first level codes as close as possible to the data, keeping them simple and precise (Charmaz, 2006). In the beginning, efforts to conceptualise were minimal. I also tried to use gerunds (words denoting action), as suggested by Charmaz (2006) as this helps the researcher to begin the analysis from the participant's perspective and prevents leaping conceptually beyond the participant's meaning and actions. Whenever pieces of text denoted the same meaning, I transferred these texts to the same code. This involved constant comparison of data in order to identify similarities and differences in the data. Examples of first level codes are given in Table 4.1.

First Level Codes	Excerpts
Receiving help from family	[My wife] prepares my tablets, she says 'these are for tonight and these are for the morning.' This is how I like my soups, my husband liquidises them for me. Mum and dad are especially helpful. Even when I go to their place ... if I am staying there, they try to cook things which I can eat.
Feeling Restricted	[diabetes] bothers you most because you cannot have this or the other. Isn't this annoying? It is like part of your life is restricted because you cannot do what you want, you cannot eat what you want. You have to be careful. It is sad that you cannot [eat what you want]. If I have Maltese bread, I will get 10 or 11 [blood sugar level], so I eat brown bread. I have brown [bread] in the fridge and I eat brown [bread].

Table 4.1   Examples of first level codes and related excerpts

4.5.5.2   *Second level coding*

This coding stage was a further step towards theory development and involved the comparison and organisation of codes produced in first level coding as well as questioning of the data. These procedures will be explained in this section. The aim was to develop categories and their properties.

In this coding stage, codes produced in first level coding were rigorously compared to each other. Similar codes were grouped together, reducing their number and creating a hierarchy of codes. The high level codes, which could later develop into categories, were associated with lower level codes which could later represent properties of these categories. This procedure is in line with what Strauss and Corbin (1998, p. 113) suggest for second level coding. Here, various similar codes are grouped into what these authors refer to as "more abstract, higher order concepts." An example of how codes of a higher order were developed from first level codes is shown in Figure 4.1.
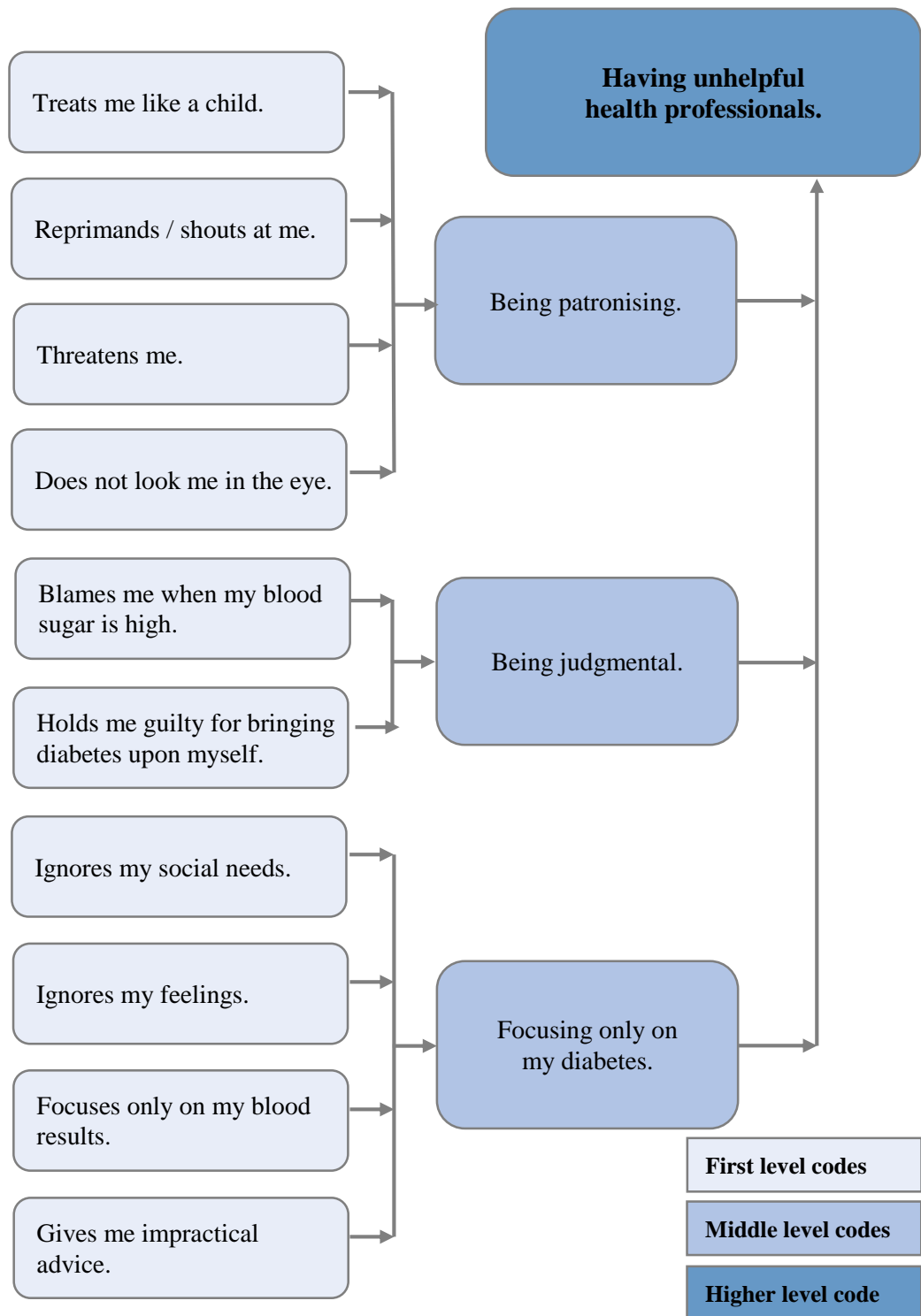
Figure 4.1   Developing a hierarchy of codes in second level coding

Once I started to identify higher order categories, I strove to develop their properties. This was done by posing questions and seeking answers to these questions from the data. This is in line with axial coding procedures proposed by Strauss and Corbin (1998). Axial coding involves asking questions such as what, why, how, when and where, to develop and explain properties, and differentiate them from others. For example, after identifying 'having unhelpful health professionals' as a potential category, I sought to find 'what' behaviours were perceived by participants as unhelpful, 'who' behaved this way towards them and 'where' did they come across unhelpful encounters. Another important question was 'with what results?' This helped me to examine outcomes of this experience.

Strauss and Corbin (1998) write how answering questions within axial coding helps to link structure (or circumstances) of a social phenomenon with its process (the actions involved). More specifically, to help the analyst connect structure and process, Strauss and Corbin (1998), came out with a coding paradigm, the basic components of which are conditions, actions and consequences. Asking questions such as who, when and where would help the analyst explore the **conditions** within which a social process occurs, the **actions** involved in the process and the **consequences** or outcomes of these actions.

I found this coding paradigm helpful with exploring phenomena. As I developed my categories, I tried to find data which, through answering my questions, would provide an insight into the three components of this paradigm. For example, in the category 'Having unhelpful health professionals,' the data I gathered helped me to understand how the approach taken by doctors towards patients was influenced by the authoritative status these held within society (condition); I could see how this influenced doctors' communication with their patients (action), and the affect this had on patients' self-management behaviour (consequence).

A key element in this phase of analysis was how questioning my data enabled me to identify gaps within in. I sought to acquire missing data by carefully choosing participants who could provide me with answers, as well as by devising the right questions to seek the required data. Again, this formed part of theoretical sampling.

As new data came in from interviews, I compared and integrated it with previous data, moving from first level to second level coding in an iterative fashion.

4.5.5.3   Advanced coding

The aim of my final coding phase was to fully integrate my grounded theory such that it would "possess explanatory power" (Birks & Mills, 2011, p. 95). This involves discovering relationships between the main categories in the formulation of theory. This phase was dominated by advanced memo writing as suggested by Strauss and Corbin (1998) and Charmaz (2006).

I started writing memos as from the first stage of coding in order to keep track of my thoughts about the data (Stern, 2010). I treated memos as provisional (Charmaz, 2006) and edited and re-sorted them as new incoming data served to elaborate or change my analytical reasoning. Memos had been attached to codes of different levels as from my initial stage of analysis.

Towards the end of my analysis, I went through all codes, properties and memos related to each category and started writing the storyline for each category, including all my reflections about it and supporting my analytic thoughts by raw data (Charmaz, 2006). This is how I developed my advanced memos. Writing my storyline this way, helped me identify and examine relationships between categories. This was central to getting my theory together. For example, a category which represented psychological responses to diabetes had 'denial' as one of its properties. I could see that denial was affecting diabetes management which was represented in another category. I could also see that individuals who denied having diabetes were more likely to be those who found diabetes management difficult, this issue being represented by yet another category. Thus, I started seeing relationships between my categories and I could provide grounded explanations of how these relationships would add up to a theory.

Constant comparison of data pertaining to different categories was a ceaseless procedure in my endeavour to generate my theory. Throughout this final stage of analysis, I tried to maintain a bird's eye view of what was happening in my data, of

how concepts were connecting together. Also, in this stage of analysis, my data collection was focused on examining and clarifying the emerging relationships. This further determined who I would choose to interview and what questions I would ask. In writing my storyline, I also reflected upon and included 'negative cases' when some data deviated from main stream. According to Charmaz (2006) this helps to refine the developing theory. Examples of negative cases and their influence on my analysis will be given in the following chapters.

4.5.6   Selecting a core category

According to Glaser (1978), identifying a core category which relates to other categories, is central to generating and integrating theory. For Glaser (1978, p. 93), a core category has high impact, and "accounts for most of the variation in a pattern of behaviour." Charmaz (2006), on the other hand rejects the necessity of identifying and working around a core category. Having been predominantly influenced by philosophical underpinnings of Charmaz's work, I did not set out to identify a core category. I believed that all conceptual categories were likely to be on equal standing to explaining my core social process. Nonetheless, as from an early stage in my data collection and analysis, I could see that the category representing the meaning of self-management amongst my participants, would most likely act as a core category. 'Self-control' which is what self-management was all about for participants, was all over the place in my data. The notion of self-control affected what participants thought about diabetes and how they acted upon it. All categories were automatically related to it. As put by Glaser (1978), this category had grab and represented the main concern for individuals in the local setting. Also, as Glaser (2007, p.14) points out, it did emerge on its own and "was hard to resist". Working around this core category did make it easier to map out my theory and establish relationships between my categories.

The above sections have discussed how I implemented different levels of coding, drawing upon recommendations of various authors of GT. Table 4.2 summaries this eclectic approach towards data analysis, presenting related decisions and the rationale behind them.

Coding stage	Authors	Recommended actions	Rationale for choosing actions
First level coding	Charmaz (2006)	Keeping codes close to the data.	Prevents conceptual leaps.
		Using gerunds.	Helps to begin analysis from participants' perspective
Second level coding	Strauss and Corbin (1998)	Comparing codes and organising them into categories and their properties.	Helps to develop first level codes into more abstract, higher order concepts.
		Using axial coding (asking questions of the data).	Develops properties of categories.
		Using a coding paradigm.	Helps to explore social processes by connecting structure with actions and outcomes.
Advanced coding	Charmaz (2006); Strauss and Corbin (1998)	Writing my storyline through detailed memos.	Helps to identify relationships between categories and develop the theory.
Selecting a core category	Glaser (1978)	Allowing the core category to emerge and working around it when formulating theory.	Helps to integrate theory by explaining the main element/concern of the social process represented in the theory.

Table 4.2   Summary of the eclectic approach used during data analysis

4.5.7   Diagramming

As Birks and Mills (2011, p. 103) suggest, diagramming helps to "conceptually map analysis" in the process of formulating and understanding one's theory. I found diagrams particularly helpful in explaining relationships between properties and eventually between categories. They provided useful, dynamic frameworks for getting my analytic thoughts together. I would always first scribble a diagram

manually and would only include the refined diagram electronically in my memos. As my analytic thoughts developed, my diagrams changed. I always kept old diagrams to be able to trace the stages I went through in developing my theory. My 'refined' diagrams will be presented in the following chapters to support my explanations of the connections between elements of my data.

4.6   Reflexivity

An important aspect of my research methods was that of maintaining a reflexive stance throughout my study, this being central to GT. This methodological issue was introduced in the previous chapter. This section elaborates on the need for reflexivity, describes the related methods employed and highlights how reflexivity led to identifying my own impact on the data.

4.6.1   Purpose of reflexivity

As shown in Chapter 3, constructivist GT upon which this study was based, upholds a relativist epistemology, thereby assuming that knowledge produced in research, incorporates standpoints of both the participants and grounded theorist (Charmaz, 2009). Moreover, as stated by Charmaz (2009), in constructivist GT, the researchers' observations and interpretations of participant data are considered subjective, and influenced by factors such as their own perspectives and experiences related to the studied phenomenon. Based on these arguments, it is suggested that the grounded theorist takes a reflexive stance throughout the research process, so as to understand the impact of his/her views and values on the research process (Charmaz, 2006, 2009; Birks & Mills, 2011). On the other hand, the role of reflexivity in exposing potential influences on data, has been debated. For example, Cutcliffe (2003) asserts that because of the complexity of human thought and behaviour, it is impossible for individuals to attain complete knowledge of the self and its influence on the research process. Reflexivity may thus be limited in addressing the role of subjectivity in interpretive work. Nevertheless, reflexive practice has long been considered as a means of adding credibility to qualitative research (Guba & Lincoln, 1989; Chiovitti & Piran, 2003; Carolan, 2003). Mills *et al.* (2006) write how, as from the beginning of the research, the researcher needs to

examine where they are in relation to the area of interest, so that they can make a link between personal and emotional issues and their future involvement with data. This link should be made explicit to both the researcher and the reader. Furthermore, Birks and Mills (2011) write that reflexive practice should be systematic, continuous and involve reflective writing, which is captured in the form of memos. Critically analysing one's reflective accounts then becomes a reflexive act.

4.6.2 Reflexive methods employed

Considering the key principles of reflexivity as outlined above, reflexive practices were initiated as from the planning phase of the research. Related notes were eventually included in memos so that they would be readily accessible at all analytic stages. A memo entitled 'influences on the data' was created before data collection. At any point in my research journey, anything that came to mind about general influences on my data was written here. These included reflections on my own impact on the data and the impact of factors, such as sampling and recruitment procedures. Reflective notes which related to each interview were also written in memos. Here, I wrote my feelings and observations before, during and after each interview. With every entry, I would reflect on how these feelings and observations could impact on my data collection and analysis. For example, when I interviewed young participants on a one-to-one basis, my entries in related memos included reference of how nervous I felt before interviewing these participants. This was due to my lack of experience with patients of this age group, which challenged my confidence in interacting with these individuals. I noted and reported how these feelings influenced my interviewing techniques.

I always made a note of group dynamics which developed in each focus group and reflected on how this could have influenced the data, such as whether there was group pressure at any point in the interview towards taking a particular stance or perspective. It seemed, for example, that when a number of participants elaborated on their negative response to diabetes, this would push discussions towards this direction and somehow mellow down and even discourage contributions reflecting positive experiences. The same thing would happen when discussions started on a positive note about the diabetes experience. As written in an earlier section, I noted

and reflected upon how my moderating and interviewing techniques impacted on my data and lessons learnt were used to improve my practice in future interviewing.

The rest of this section is focused on sharing with the reader the general influences on my data, as a result of my personal characteristics, as well as my preconceived ideas about diabetes self-management.

4.6.3   My influences on the data

I am Maltese and a nurse by profession, although I have spent the majority of my professional career as a lecturer in nursing. Unlike many Maltese nationals, I do not have any relatives who have diabetes, such that my exposure to the experience of this condition, has been mostly related to my nursing career. Much of this exposure has been with patients on medical and surgical wards who were hospitalised due to complications of this condition. Thus, a lot of what I learnt about the diabetes experience was related to the suffering involved in its later stages. I frequently came across individuals who had gone blind, had amputations, had suffered renal failures or had experienced severe hyper- or hypo-glycaemia due to uncontrolled diabetes. This immediately highlights my point of departure in this study. For me, diabetes signified suffering and diabetes self-management was all about impossible challenges. I was poorly prepared to hear alternative points of view - and when I did, they confused me.

My first focus group consolidated my negative perceptions about diabetes, and I somewhat felt comfortable in my understanding of the condition. However, I was taken aback during the second focus group where a number of participants talked positively about their experience, referring to diabetes as 'something you get used to'. Upon reflecting on how I had conducted this focus group, I realised that I had continued to ask these participants questions trying to get what I felt were the 'more realistic' negative perceptions. I then realised that my preconceptions had influenced my interviewing techniques.   As from that point, I tried hard to adapt my interviewing method and to remain as neutral as possible when analysing my data. I needed to develop 'sensitivity' towards positive experiences, besides negative ones.

Being a nurse was likely to influence not only my sensitivity towards my data, but also the type of data which participants offered. I presented myself to participants as a lecturer in nursing and as a researcher. In view of my nursing background, some participants might have been reluctant to complain of nursing care received. Also, the fact that I could publish research reports which could instigate needed changes in practice or policy, may have prompted participants to bring forward their complaints. I further observed, that when participants did express negative experiences about the care they received from health professionals, I had problems writing these down. These professionals were my colleagues and they had cooperated with me during my data collection. Consequently, reporting complaints about their services felt like letting them down. My role was to remain true to the data, while being fair to my colleagues. Therefore, I made sure that participants' positive experiences of healthcare would be reported alongside any negative ones.

Having worked within healthcare teams may have led to my having preconceived ideas about how these work. This may have affected my interpretation of data related to service provision. For example, having experienced power relationships with doctors in my nursing career may have influenced how I interpreted patients' accounts of their own experiences with these professionals. As stated by Mantzoukas (2012) with reference to critical ethnography in nursing research, researching a context that is familiar to nurse researchers can pose methodological and ethical challenges as these may find it difficult to dissociate themselves from the research context. Being aware of this problem, I was careful on how I interpreted and reported related data. Besides discussing my analysis with one of the assistant moderators, as will be explained below, I actually gave her the related chapter to read so she could check my reporting style. This was seen to be fine and no major changes were recommended.

On the same line of argument as above, identifying cultural trends in my data was quite challenging since I am Maltese. Malinowski (1950 cited in Spradley, 1979, p. 9), points to how natives tend to take fundamental cultural assumptions for granted. In fact, most of the cultural implications in my findings started to stand out upon comparing my findings with the literature. My supervisors, being foreign to the Maltese culture, also helped me note patterns in the data which were unlikely to

feature in a similar study carried out in the UK. Reflecting on this limitation, led me to make the required effort to learn more about my own culture and identify related trends in my data.

4.7 Ethical considerations

As stated by Iphofen (2005) whenever research has an effect upon the lives of individuals, ethical issues need to be considered. This involves value judgements, and the role of ethical guidelines is to help the individual assess these values and make informed choices related to them (Thompson, 2000). This section discusses the various ethical considerations made in this study, the values upon which these were based and the related ethical procedures which were followed.

4.7.1 Approvals and consent

Ethical approval for the study was sought from Bournemouth University (where studentship for this study commenced), the University of Hull (where studentship was completed) and the University of Malta (where data collection took place). Approval from the hospital and primary healthcare departments and from consultants and nurses involved with patient care, was also sought to access registered patients. Submission for ethical approval to conduct focus groups and one-to-one interviews was carried out separately and therefore approvals were obtained twice, once for each data collection procedure. A list indicating all the approvals gained is in Appendix 10. Approvals from universities are included in Appendices 11 – 13 and a few examples of the other approvals obtained are included in Appendices 14 – 17.

The process of obtaining informed consent from participants supports the principle of respecting autonomy. This is related to the fair distribution of power between the researcher and participant. Seeking 'rich' data to answer research questions involves some form of intervention, which as stated by Iphofen (2005) always involves an element of exploitation of the research participants and their meaningful spaces. This may include asking participants to share personal, often intimate experiences and feelings. Hence, while the researcher retains the power to choose and adapt methods that seek the necessary data, the participant should be given the power to

choose whether to participate and contribute this data (*ibid*). Allowing participants to preserve their autonomy in this regard, is a way of acting democratically in the conduct of research. On the other hand, as Iphofen (2005) continues, it is often impossible to guarantee complete autonomy, as this would mean that individuals perceive no pressure to participate. This is difficult to achieve in certain situations, such as that occurring in this study, where potential participants were approached by their health professionals.

All participants in this study were informed about the purpose of the study, the nature of data collection to be used, and their right to refuse to participate or withdraw from the study at any stage of the data collection. The patient information sheet addressed the most salient issues which participants needed to know before deciding to take part (Appendices 2 and 8). A balance was sought between giving too much or too little information. As Bryman (2008) points out, in obtaining informed consent, the main issue of concern is how much information to give. Too much information could act as a disincentive, such that, for example, participants may think that their involvement is too complicated. On the other hand, too little information may be construed as deceptive. Furthermore, Allmark *et al.* (2009) argue that fully informing participants of the nature of their participation may not be possible in qualitative research. This is because in-depth interviews can delve into areas which would not have been anticipated at the start of the study. This is particularly the case with focus group interviews where the subject of discussion can take unprecedented directions. Also, during in-depth interviewing, participants may find themselves discussing issues they would have rather kept silent about (Allmark *et al.*, 2005). Thus, in these situations, 'informed' consent becomes a relative term and the use of written consent at the beginning of the research, may hold limited value. In view of this, besides obtaining written consent, at the end of each interview participants were verbally advised that they could retract any information they had contributed at any time, if they wished. Should this be the case, they were asked to contact me about this.

Participants were asked to sign two consent forms. During recruitment procedures they were asked to give written consent for the researcher to be provided with their personal details. Before they engaged in the focus group discussion, or one-to-one-

interview, they were asked to sign a consent form indicating the conditions under which they had been asked to participate, and their agreement to take part in the interview.

4.7.2 Confidentiality and anonymity

As stated by Goodwin (2006), ensuring confidentiality is needed to safeguard participant privacy. The author notes that this may be problematic in qualitative research because what people say may need to be published word for word. Thus, in the following chapters, fictitious names will be used when presenting participant data, so as to protect their identity. As stated by Morgan and Krueger (1993), another issue of concern is the protection of confidentiality from other focus group members. I could not ensure that other individuals in the focus group would not disclose information, and this was clearly explained in the information letter. Nevertheless, ground rules about confidentiality were set at the beginning of each meeting. Participants were given the option not to state their real names when introducing themselves to the group. This would also ensure that their identity would not be revealed on the recordings.

Data were carefully handled and stored. Recordings, consent forms, information sheets and any other data were stored in a locked cupboard to which only I had access. All electronic data were stored on a password-protected personal computer. The transcriber who also needed to access the recordings was asked to sign a confidentiality agreement.

4.7.3 Protecting participants' safety

Procedures to promote safety were based on the principles of beneficence and non-maleficence. Beneficence relates to the good that comes out of the research, while non-maleficence is about potential risks to participants (Fouka & Mantzorou, 2011). These authors explain that researchers must consider all possible consequences from their research and make choices to balance out risks with proportionate benefits. As Iphofen (2005) points out, in qualitative research, this may mean considering how

much interference in participants' life is worth creating to reap the benefits of the data collecting intervention.

In terms of benefit, this study was planned to contribute evidence to the existing body of knowledge related to self-management support and, in the process, help to improve related health and social policy, as well as healthcare practice in Malta. As anticipated, participants actually enjoyed the focus groups and felt they had learnt from them, through sharing their experiences with group members. Consideration was given to the potential harm to participants which this study could cause. For example, Allmark *et al.* (2009) point to how in-depth interviews could become emotionally intense. Debates about boundary issues in these circumstances remain, such as whether the researcher should also act as a counsellor when dealing with emotional distress during interviews (Allmark *et al.,* 2009). As a ground rule, I chose to employ empathy and a non-judgemental attitude throughout and I dealt with significant participant concerns, as outlined below.

Addressing participants' well-being during interviews sometimes entailed having to manage a dual role of researcher and health professional. For example, when individuals revealed misconceptions related to diabetes, this was briefly corrected during the interview. In cases where individuals expressed concern, such as about poor diabetes control or other health issues, these were addressed individually after the focus group, or after switching off the recorder at the end of a one-to-one interview. When necessary, these participants were referred to a diabetes specialist nurse or other sources of medical care. On a couple of occasions, I called the participant some days after the interview, to check on how the problem was followed up. To address the principle of non-maleficence, it was also planned that should a participant become unduly upset during a one-to-one interview, this would be stopped and in the case of a focus group discussion, one of the assistant moderators would accompany the person out of the room, and stay with him/her until he/she settles down. This procedure was never needed.

4.8 Achieving qualitative rigour

As stated by Thomas and Magilvy (2011), achieving rigour in a qualitative study is a way of establishing trust in the findings of the project. Most of the procedures aimed at achieving rigour in this study have been discussed in previous sections. The purpose of this section is to explain how these strategies were planned to meet different criteria related to rigour. In order to simplify such a complex topic area, the framework suggested by Beck (1993) will be used. This, in turn, is based on the widely quoted writings of Guba and Lincoln on this subject area. Beck (1993) identifies three main standards of rigour, namely **credibility, fittingness** and **auditability**.

4.8.1 Credibility

According to Beck (1993, p. 264) credibility relates to how "faithful the description of the phenomenon is." On the same lines, Guba and Lincoln (1989) state that procedures which enhance credibility are aimed at ensuring that reconstructions of realities by the researcher are true to or match the constructed realities of participants. As discussed in the previous chapter, considering the concept of co-construction of data, 'reconstructions' of participants' realities will always be relative. The aim would be to achieve the closest possible match. As stated by Cooney (2011), a mechanism to enhance credibility is built into GT methods. For example, Elliott and Lazenbatt (2005) describe how concurrent data collection and analysis, as well as checking emerging categories against data which is collected from participants, is a way of ensuring that the emerging theory truly represents participants' views and experiences. Chiovitti and Piran (2003) refer to how credibility is enhanced when concepts introduced by participants are used to modify and develop questions in an interview, changing the interview schedule in the process. All these procedures formed an integral part of this study.

Another well-quoted procedure for enhancing credibility is what Guba and Lincoln (1989, p. 238) call "member checking". This involves testing the data, its interpretations and conclusions with study participants. However, this procedure as a means of validation, is debatable. For example, Long and Johnson (2000) point to

how participants may have changed their views over time due to changes in their situations, or even as a result of participating in the research. In fact, in this study, a male participant was interviewed on a one-to-one basis some months after he had participated in a focus group. In between interviews, this participant changed his job. In view of this, by the time of the second interview, I noticed that this participant had completely changed his opinion about the influence of the work environment on self-management. Burnard *et al.* (2008) also note that some participants may not recognise elements of the emergent theory as each would have contributed only a portion of the data used for theory construction.

In view of the controversies surrounding this issue, I did not return to my participants with my analysed data, but, as suggested by Krueger (1998) I carried out a simple form of member checking procedure at the end of each focus group. Here, one of the assistant moderators read out a summary of the points raised during the interview, and participants were asked to state whether they agreed with the summary. There were instances when participants proposed some changes or additions. After analysing each focus group, I read this summary to make sure that my analysis had covered all points included in the summary.

Chiovitti and Piran (2003) also suggest enhancing credibility by using participants' words when formulating theory. This helps prevent inaccurate representation of their meaning. I tried using participants' language when naming my properties and categories (in a translated form), avoiding technical words or phrases. I also used *in vivo* codes where necessary.

The practice of reflexivity is also widely quoted as a method of enhancing credibility (Beck, 1993; Guba & Lincoln, 1998; Chiovitti & Piran, 2003). This is because as Guba and Lincoln (1998) state, any construction that emerges is a joint one. Hence, as mentioned in an earlier section, my potential influence on co-constructed meaning was considered and reported.

Finally, Guba and Lincoln (1998, p. 237) propose 'peer debriefing' as a means of engaging with another person in extensive discussions about one's findings, tentative analysis and conclusions. This has various uses. The peer may pose searching

questions to help the researcher understand the role of his/her values or preconceptions on the analysis and gives an opportunity to the researcher to discuss the analytic steps which are to follow. I carried out these discussions with one of the individuals who was helping out with the focus groups. This person was a colleague of mine and had previously carried out qualitative research, but had little experience working with individuals with diabetes. The advantage of discussing my findings with this person was that she had knowledge of the focus group members and the general climate of the discussion. Therefore, she could easily relate to my data. However, this may also have contributed to preconceived ideas on her part, which could have influenced our discussions.

4.8.2 Auditability

Auditability is about keeping a comprehensive record of all methodological decisions made during the research process. This record should be sufficiently detailed to make it possible for other researchers to repeat the same study in a similar fashion, if they want to. Guba and Lincoln (1998, p. 242) divide this process into 'dependibility' and 'confirmability.' In the former, the researcher documents any change in methods or shifts in the construction of theory, which become necessary, such that reviewers can track and judge the decisions made. This is important in a flexible, qualitative enquiry as changes are often necessary within an evolving design. Such changes have happened in this study and are documented in this write-up, such as changing the composition of the focus groups towards the end of data collection, from a mixed gender to a female only focus group. Confirmability means ensuring that all sources of data and procedures involved in their analysis, together with interpretations made are made explicit for the outside reviewer to inspect. I documented my procedures, interpretations and decision-making trail of my analysis in my memos and I explicate all necessary detail in this write up.

4.8.3 Fittingness

To judge fittingness, Beck (1993) suggests asking whether the study results fit the data from which they were generated. For this purpose, I repeatedly referred to my data when determining my categories, utilising constant comparison. To enable the

reader to judge fittingness, I used excerpts to illustrate and support my findings. Once it is confirmed that the theory fits its data, fittingness becomes concerned with demonstrating that the findings (or theory) may have meaning to others in similar contexts and situations. Guba and Lincoln (1989) refer to this as 'transferability'. Because findings are considered to be contextual, transferability of findings would be dependent on the similarity of contexts and as Guba and Lincoln (1989) declare, such transferability will always be relative. The aim of the researcher would be to make transferability judgements by other researchers possible. This is achieved by providing "extensive and careful description of the time, place, context and culture in which the hypothesis were found salient" (Guba & Lincoln 1989, p. 241). All these details are included in this study, particularly in the forthcoming chapters which address findings. Before proceeding to these findings and concluding this chapter, the section below will introduce the method by which findings will be presented and discussed in this thesis.

4.9 Moving from methods to findings: Setting the scene

The role of this section is to introduce the following chapters by linking information from this chapter with that which is to be presented in the chapters which follow. The section first presents the results of sampling and recruitment procedures explained in this chapter and then introduces the manner by which results of data analysis will be presented and discussed in Chapters 5 - 9.

4.9.1 The sample

Data collection extended from February 2012 to December 2013. A total of six focus groups and twelve one-to-one interviews were conducted. Of the latter, six interviews were held with individuals who had participated in a focus group and the other six involved those who were new to the study. Focus groups lasted between 1.5 – 2hrs and one-to-one interviews lasted 1 – 1.5hrs. It was found most difficult to recruit younger participants for reasons mentioned earlier (see Section 4.4.1), as well as female participants who often referred to family responsibilities which held them back from participating.

The final sample consisted of 52 Maltese individuals with Type 2 diabetes and was characterised by a more or less equal distribution of male and female participants. It also represented a good mix in terms of occupational status, duration of diabetes, as well as source of follow-up care. Most of the participants were over the age of fifty, which reflects the situation in the target population, since Type 2 diabetes occurs later in life. Although only four participants were less than forty years of age, three of them were interviewed on a one-to-one basis, hence providing a considerable amount of data. Thus, the experiences of these individuals are well represented in the findings. Most of the participants were taking oral hypoglycaemic tablets as part of their diabetes management, this being the most common approach to treatment in individuals with Type 2 diabetes (IDF, 2012). Although all levels of education were represented in the sample, the overall educational level was low, with only fourteen (27%) participants reporting having attained post-secondary or tertiary levels of education. This also reflects the situation in the target population, since, according to the last population census carried out in 2011, educational level is significantly lower amongst the older Maltese individuals (NSO, 2012). Details of the characteristics of the whole sample and of individuals attending focus groups and one-to-one interviews are included in Appendices 18 – 20.

4.9.2 Topic areas to be covered

The next four chapters (Chapters 5 – 8) will present and discuss findings of the study. Findings have been organised into four categories and each of these chapters will represent one of these categories. Chapter 5 is about participants' perceptions of diabetes self-management. Amongst other issues, this chapter describes participants' views of what good diabetes self-management entails. This category represents the core category of this study, since all other categories are somehow related to the 'strategy for self-management' which participants came up with. For example, Chapter 6 explains the extent to which participants were successful in managing their diabetes the way they felt they should and presents the outcomes or consequences of successes and failures in such management. Chapters 7 and 8 then refer to factors within the Maltese social environment which seemed to influence participants' coping abilities or their ability to implement their self-management strategy. These two chapters will delve deeply into cultural issues and the mechanisms by which

they influenced coping. Overall, the chapters will address what participants perceived as being their 'job' in self-management (Chapter 5), the outcomes of succeeding of failing to carry out the 'job' well (Chapter 6), and the cultural factors which determine the level of 'job performance' (Chapters 7 and 8). Chapter 9 then integrates these findings into an emergent substantive theory.

4.9.3 Chapter structure

Each of the following four chapters will first present findings related to the category they represent (this is Part 1 of the chapter), and then discusses these with reference to the literature (in Part 2). Hence the literature search for these chapters was consistently led by the data. Diabetes-related literature was used as much as possible but when this was lacking, concepts were examined against general literature in the area. The inclusion of seminal work in discussions means that old references are used at times. It was important to include all the findings presented in this thesis, as they all contribute to the development of the substantive theory. However, it was not possible to discuss all of the included findings in depth. Decisions had to be made about selective discussions.

Although all subgroups of a category are properties of that category, I have given different names to different levels of properties. The first group of major properties are named 'subcategories' and subgroups of these are then named 'properties'. Not all subcategories are similarly complex and some may have just one or even no properties to explain them. This diversity is illustrated in a diagrammatic representation of the category, which is included in the beginning of each chapter. Furthermore, before addressing individual categories in separate chapters, Figure 4.2 combines all categories and their multi-level properties together to illustrate how data in general have been organised in the process of theory development. A specific colour code will be consistently used in diagrams which represent or illustrate categories and their properties.

Figure 4.2   Organisation of the multi-level codes used for developing theory

CATEGORY 3:
Being in a helpful environment.

CATEGORY 4:
Having access to care and resources.

Subcategory:
People's views about my diabetes.

Property:
Being labelled, judged and discriminated against.

Property:
Losing control over disclosure.

Property:
Disclosing/not disclosing - being helped/being hindered.

Subcategory:
Being affected by family.

Property:
Family as enabling.

Property:
Family as disabling.

Subcategory:
The role of food culture.

Subcategory:
Organisation of my care.

Property:
Requiring better consultation visits.

Property:
Receiving incomplete care.

Property:
Opting for private care.

Subcategory:
My relationship with health professionals.

Property:
Having insensitive health professionals.

Property:
Having helpful health professionals.

Subcategory:
Having access to resources.

Property:
Coping financially.

Property:
Having access to information.

Figure 4.2   Organisation of the multi-level codes used for developing theory (cont.)

In the following chapters, findings will be accompanied by translated excerpts from participants. Although these excerpts come from the majority of participants, not everyone's contribution is represented somewhere by an excerpt. I constantly selected excerpts which best represent the arguments being put forward. Nevertheless, the underlying thoughts/perceptions would often be similar to those of other participants. Also, participation from individuals was not equal, such that those taking part in a focus group and a one-to-one interview, provided more data than others. Hence, the number of excerpts representing a single person's contribution tends to vary. A strategy has been used to present and code these excerpts. Details of this strategy are given below:

1. Since Maltese individuals tend to use English words and phrases in their conversations (switching from one language to another as they speak), I have chosen to quote English words *in vivo*. These are written in italics. This means that words in italics within excerpts are words which the individual would have said in English in the middle of an otherwise Maltese conversation.

2. …. refers to participant's pause in the conversation.

3. […] means that some words have been removed from the conversation.

4. Names written at the end of the excerpts are fictitious although the same name is consistently used for the same person.

5. Codes are given near fictitious names, such as 'Saviour, 30Int' or 'Monica, 50FG'. The number in the code represents participant's age, such that for example 30, would mean that the individual's age was between 30 and 39 years. The only exceptions are numbers 18 which represents ages 18 – 29 years and 70 which represents 70-75 years. The abbreviation 'Int' refers to the excerpt coming from a one-to-one interview and 'FG' means that it was taken from a focus group interview.

4.10   Conclusion

My epistemological principles related to perceptions of support need determined my decision to use GT as an approach to investigation. Consequently, methods I used reflected central features of GT, such as theoretical sampling and constant

comparison of data. Methodological decisions were further aimed at enhancing rigour and producing good quality data, while respecting ethical boundaries. This involved considering advantages and limitations related to every methodological step that lead to theory formulation. In the process, I had to compromise, since no method is perfect and resources were limited. Choices had to be made and this chapter gave a detailed account of how these translated into action. The aim was to come up with a substantive theory which, in light of the limitations involved, could best represent participants' views of perceived needs for diabetes self-management support. My findings have identified a social process involved in developing these views on support needs. The following chapters are dedicated to explaining this process.

Chapter 5

CATEGORY 1: CONTROLLING MYSELF, ADAPTING TO MY DIABETES

Part 1: Findings

5.1 Introduction to findings

This chapter is about lay definitions of diabetes self-management. It presents results related to what participants thought that diabetes self-management involves, the kind of challenges it presents and whose responsibility they felt it should be. Although diabetes self-management is widely defined in the literature, I set out to examine what this concept means to Maltese individuals with diabetes, believing that providing support for self-management involves learning about individuals' own expectations of such management. As I analysed my findings, I realised that all emerging categories were connected to central concepts within participants' definition of self-management and that from within this definition, emerged a basic social process which underpinned my evolving theory. Consequently, I treated this lay definition as a core category which I called 'Controlling myself, adapting to my diabetes.' This chapter is about this core category.

Part 1 of this chapter explains the four subcategories of the core category represented in this chapter. These subcategories are varied in complexity and describe different concepts within participants' definition of self-management. The first and second subcategories describe the concepts of self-control and adaption respectively. The third subcategory is about perceived levels of difficulty in managing one's diabetes. This is the most complex subcategory and includes a number of properties. The last subcategory presented in this section is related to responsibility for self-management. Figure 5.1 illustrates all the components of this core category. Elements of the subcategory 'Managing through self-control' which explain what participants felt

that self-management involves, will be addressed again in the following chapter. These elements are central components of the substantive theory developed in this thesis and are therefore analysed in detail in a separate chapter. A discussion of findings is presented in Part 2 of this chapter.
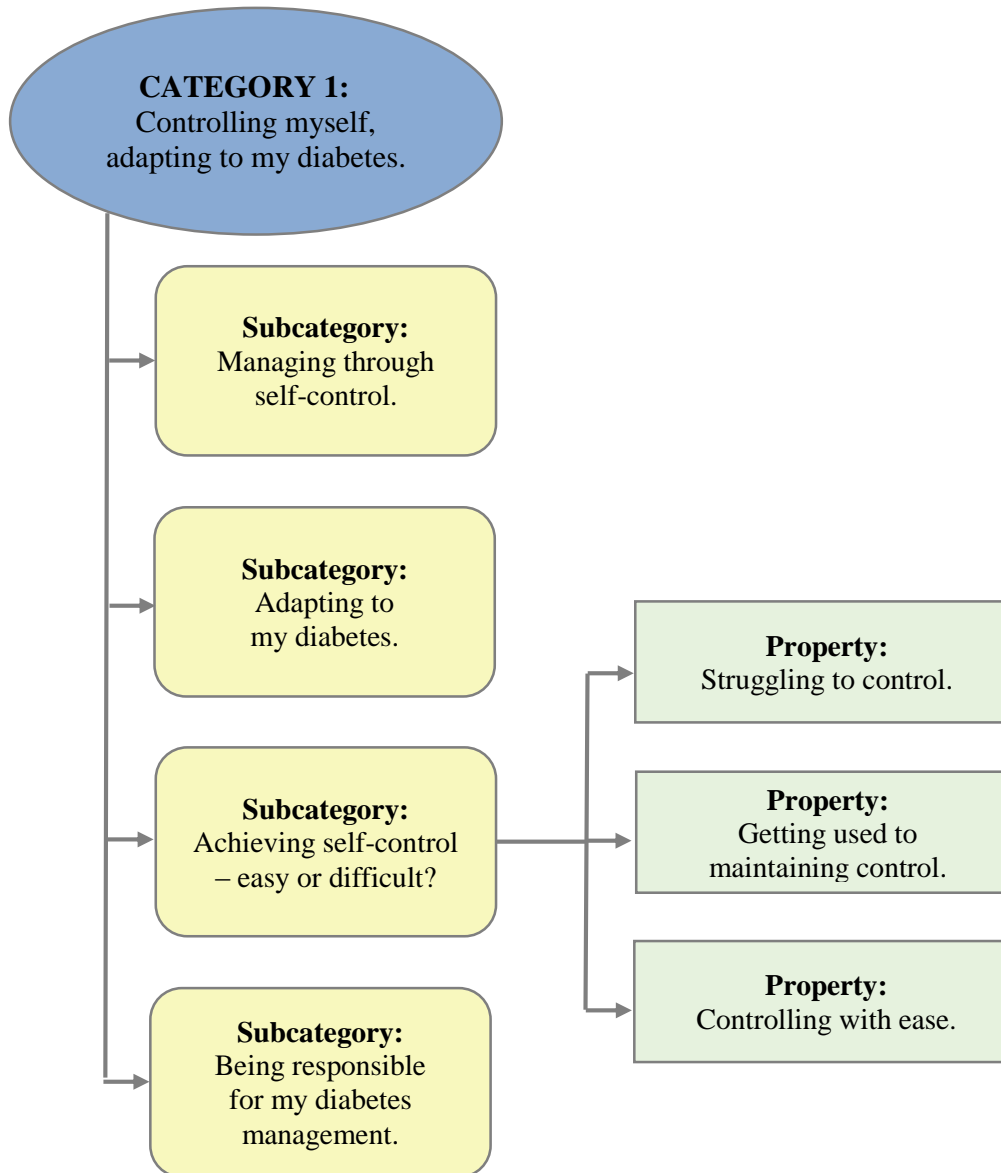
Figure 5.1   Elements of Category 1 including related subcategories and properties

5.2   Subcategory: Managing through self-control

This subcategory is about participants' views regarding self-control as a requirement for diabetes management. Discourse about what to do or not to do to manage one's diabetes dominated all interviews. Upon being asked what diabetes self-

management means to them participants unhesitatingly mentioned an array of behaviours which individuals with diabetes need to carry out in order to manage their condition. You have to eat in moderation, choose what to eat, and avoid missing meals. You should find time to exercise and meticulously adhere to your medication regime. You cannot miss follow-up appointments and you need to establish a pattern for self-testing. Participants strongly felt that sticking to such a behavioural regime requires self-control. In fact, the word 'control' was commonly used in discussions about self-management and echoed continuously during conversation. To this extent, 'self-control' seemed synonymous with diabetes self-management and using the term 'control' when naming this core category became inevitable.

> [to manage diabetes, you need to] walk and you need to control. That is what you need, control [….] control yourself in terms of food and exercise. (David, 60FG)

Participants mentioned strategies which made control of behaviour easier, thereby facilitating their self-management. These included the use of flexibility which helped them adapt their self-management to their preferred lifestyle, or particular needs. This would include, for example, allowing themselves a little extra food during a social occasion or when eating out and making up for this with exercise after the event, to get their blood glucose back to normal. This linked closely to planned management which was an approach perceived as facilitating adherence to behavioural regimens and would involve, for example, keeping a healthy low calorie snack in the refrigerator to eat when hungry. Flexibility and planned management will be addressed and discussed in more detail in the next chapter. Besides behavioural control, controlling (or managing) one's thoughts was also construed as having a central role in diabetes self-management.

Participants conveyed that, despite their free flow, thoughts can be consciously controlled. Thoughts may influence mood, attitude and behaviour and participants felt that they should use thought management as a means towards this end. During interviews, thought management featured highly in discussions about diabetes self-management, even though the subject was not tackled as extensively as behavioural

management. Two aspects of thought management were highlighted; one being the importance of avoiding stress and the other developing the right mind-set about having diabetes.

Stress is associated with emotional upset and, as participants explained, it tends to compromise one's will to maintain control over behaviour. It was thus, repeatedly referred to as a major obstacle to diabetes self-management. During stress, individuals reported losing general motivation to maintain behavioural control. Moreover, as shown in the excerpt below, stress was considered to compromise will power as the mind, over-saturated with negative thoughts, becomes incapable of dealing with everyday issues. The individual thus focuses on the stress-provoking problem and efforts towards diabetes management are put on hold. As the second excerpt points out, the problem is that diabetes management cannot be shelved until stressful situations are dealt with.

> In my opinion, when life is normal, *you can control* [diabetes], *you can fight it*. The problem is […] stress. *When you are under stress,* this applies to me, at least, *I lose control,* I turn to food. As soon as I am a little stressed, [give me] a good plate of pasta and just let me be … *If my state of mind* is normal, or nothing is worrying me, and I am calm, then *all right,* my *aim* is to fight my diabetes and to be careful. If I have some worries, [like, for example] I have shops of my own, and when a problem arises, its goodbye to my diet. *I treat* that problem and I forget about my other issue [my diabetes]. That is how I deal with it, I know it is not right … (Alfred, 40FG)

> ..but obviously, [diabetes] *is not going to hold back* [and tell you] *"Ok, you take care of your stress problems and then I start attacking you again."* It is there, *it is there for life, it's a blind killer* and that is it. (Daniel, 40Int)

Some participants also commented that stress takes up so much mental energy that, in times of stress, they feel depleted of the strength required to plan, prepare and execute activities related to diabetes management. With reference to a stressful period in her life, a female participant gave the following account:

> In the sense that, though I usually like cooking, during that [stressful] period of time I used to look at my vegetables in the fridge, and say

> "Yes I need to cook [my soup]." But, by the time I came to do it, it was like I was going to do something really huge, when normally I just get up and do these things as part of my routine. (Sue, 60Int)

Because stress was perceived as such a strong antagonist to diabetes management, individuals talked about the need to avoid it. Avoiding stress related to normal life circumstances is not always possible, but some individuals referred to strategies they used in this respect. Examples will be given in the next chapter which will address this subcategory in more detail. However, most discussions on this topic focused on how one could avoid stress related to having diabetes itself, since diabetes could be a significant stress provoker. Diabetes was construed as inducing stress besides being affected by it. For participants, the mind was centrally important in managing this condition and they seemed to make a conscious effort not to get carried away by diabetes-related thoughts, such as those related to diabetes complications.

Besides the need to manage thoughts in order to reduce stress, participants spoke of another approach to thought management, that of developing a positive mind-set towards diabetes. For participants, this meant not only controlling *how much* one thinks of his/her diabetes, but also *the way* one thinks about it. Developing a positive mind-set was seen as shaping what one thinks about himself/herself as a person with diabetes. It meant doing away with negative emotional reactions towards having diabetes. Rather, one should consider diabetes from a positive, as well as a realistic perspective. Speculations about this issue reflected two categories of thought which are interrelated. These include **positive thinking** and **accepting diabetes**.

Thinking positively about a potentially negative experience was construed as a way to develop a positive attitude towards it. Positive thinking is about being optimistic. The commonest way by which participants reported being positive was through comparing their situation with case scenarios which were worse than theirs.

> When I realise that there are others out there who have children with cancer, I say to myself "Why should I be kicking up such a *fuss*? *I am receiving treatment* [for this condition], unlike those for whom there is no hope" … I say there are others who are much

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worse than me, so I have nothing compared to them. *I don't make a big deal out of it.* (Lorraine, 50Int)

Positive thinking was seen as helping individuals accept their diabetes. Participants spoke about acceptance as a prerequisite to getting used to a life with diabetes. The Maltese term used by quite a few was "*trid tirrassenja ruhek"* which can technically be translated as "avoid struggling against it mentally," "give in to it" or "resign yourself to it." This refers to the need to control one's innate inclination to protest against or deny one's diagnostic label of diabetes. The way individuals spoke about the need for acceptance also denotes the ultimate realisation that once you have diabetes, it is there for life. Participants viewed acceptance as a process, requiring time and effort.

At first, I took it badly. I was not born with it. But now I [have] got used to it. I am normal. You need to accept it, you know. [Diabetes] stays with you till the end, like the doctors told me. Now that it is there, it [stays] there. (Frankie, 18Int)

Controlling thoughts and behaviour in the ways mentioned above was considered necessary in order to successfully *adapt* to diabetes. This is explained in the section below.

5.3 Subcategory: Adapting to my diabetes

For participants, adaptation to diabetes meant moving on with one's life, while caring for one's diabetes. Adaptation was construed as the ultimate objective of self-management. As shown in the above sections, participants conveyed how adaptation requires a specific approach towards thought and behavioural control. For example, flexible management enables modification of a diabetes regime to one's preferred lifestyle. Minimising stress, thinking positively and accepting diabetes enable the individual to develop a positive mind-set towards diabetes, which allows him/her to move on with life as desired. For participants, moving on with life meant maintaining normality, maintaining previous roles, previous relationships, preferred activity. It meant still doing housework, still meeting friends at the bar, still eating out … despite having diabetes and while still caring for it. But, as conveyed by

certain participants, this may not be possible if an individual feels negative and stressed about diabetes, denies the reality of his/her condition or fails to be flexible in his/her behavioural management.

Since adaptation as a concept was so important to participants, this section presents data excerpts which highlight its meaning to them, its importance and its dependency on flexibility and thought management.

> Even though one is a diabetic, one should not blow things out of proportion and keep on harping how "My life is over." Do you know what I mean? You try to live, you say I will live as I need to live, I will reduce my intake of certain things that are not good for me, or eat these in moderation, otherwise are you not like everyone else? If you have housework [to do], you have to do it. (Cathy, 50FG)

> For the past two years or so, I felt that [diabetes] is *not top in [my] mind*, that you [...], I mean, you know that you are diabetic, but you try to live a normal life. Obviously you try not to make a pig of yourself, and that sort of thing … like, when going out with my friends for a drink, I will still drink with them but in moderation. (Stephen, 30Int)

Certain participants, some more than others, experienced challenges to achieve the required self-control and they struggled to effectively handle thought and behavioural management. These experiences are addressed in the following section.

5.4 Subcategory: Achieving self-control - easy or difficult?

This subcategory focuses on how individuals managed their diabetes at different levels of difficulty. Although participants held similar views of what self-management is, the perceived difficulty with carrying it out was noted to vary amongst them and could range from one extreme to the other. Three levels of difficulty in managing diabetes were identified and will represent the properties of this subcategory. Participants were either found to 'struggle' to self-manage (denoting highest level of difficulty), to 'get used to' managing (denoting medium level of difficulty) or to manage 'with ease' (denoting lowest level of difficulty). Participants were categorised according to the level of difficulty they were found to experience. Care was taken when categorising individuals. To decide which level of

difficulty an individual was perceiving, all the statements about diabetes control which were made during the interview/s by that same individual, were considered. The three levels of difficulty with self-management are explained in more detail in the next sections.

5.4.1   Property: Struggling to control

Besides labelling their diabetes management as 'very difficult,' participants in this group would repeatedly refer to problems with such management. Life experiences seemed to rob these individuals of the will power they required to make the necessary lifestyle changes or to adapt to their diabetes. This section explains different ways by which individuals in this category found diabetes management difficult. The aim is to highlight these participants' perspectives of achieving change for diabetes management.

For most individuals, being diagnosed with diabetes meant having to alter their eating habits. However, for those in this group who struggled to control, the required change was often perceived as 'drastic.' They referred to this as a 'complete' change. This seemed to render dietary modifications particularly challenging. These participants believed there was a marked difference in the way they lived their life before and after being diagnosed, with thoughts of deprivation dominating their current lives with diabetes.

> Sort of ... this is not good for you and this is not good ... you would have become used to your previous eating habits over a very long period of time, and then at fifty, you have to completely change everything that you have been used to do and I found this very difficult. (Christopher, 60FG)

It was noted that individuals who viewed diabetes as imposing a drastic life change, would also talk about themselves as being great food lovers. This may have been the actual reason why they had to change their diets drastically, or it may have influenced the way these individuals perceived the change. Obsession with food was expressed in a number of ways.

> You find yourself in this situation - I have diabetes, I have high cholesterol, I have high blood pressure, I had a heart attack, I smoke ... in other words I have an explosive *cocktail*. If I had to go ahead and say "I will control all these," I might as well bury myself because there will no longer be a reason to live [....] there are people who eat to live but then there are others like me, who live to eat. (Alfred, 40FG)

> I am a great food lover. For me, every single thing that I deny myself, any day, is a struggle. It is a struggle, a struggle which I cannot get used to, but have come to accept. (Daniel, 40Int)

Finally, self-management also seemed burdensome when accompanied by feelings of failure, such as when attempts to achieve behavioural control were unsuccessful. With some participants, feelings of failure would be accompanied by a serious lack of self-confidence. In these situations, the belief in one's ability to make change was evidently very poor.

> I am not able to control; I am not. [....] If my wife did not control me ... I think I would have been dead a long time ago, because even if I see a piece of chocolate I would definitely want to eat it. That means my wife actually controls me. (Manuel, 70FG)

Feelings of failure also resulted from being unable to normalise blood sugar levels, despite being committed to modify behaviour. A female participant spoke of how, despite her repeated efforts to control her diet, her blood sugar remained persistently high. Others described the erratic nature by which their blood sugar responded to their food intake. They would find high sugar levels after having been faithful to their dietary regimen, while sometimes sugar levels would remain within normal limits after they would have eaten abundantly. For these individuals who were unable to understand the mechanisms of their diabetes, managing their condition became a frustrating ordeal.

> It is difficult for me [to control my diabetes] because I do not eat bread and this sort of thing, not even sweets. This year I have not even been to a party, that is, I did not eat much sweets and I find my blood sugar high. I do not know why. So it is difficult. (Angela, 60FG)

5.4.2   Property: Getting used to maintaining control

Most participants fell within the group representing this 'medium' level of difficulty. For them, self-control within diabetes management was characterised by a number of difficulties and challenges, but it was also an experience which they somewhat got used to. The challenges they encountered became less burdensome by time. Also, although these individuals projected aversion towards their more restricted life, they did not seem to be overcome by it.

> [you get used to the fact] that you are really not as unrestricted as a
> healthy person. It's true, you are not free, but then this gets within
> your system to such an extent, that not even this would bother you.
> (Sue, 60Int)

Getting used to controlling oneself was not mentioned so categorically. In fact, while participants in this group described situations which they had become used to, they also pointed to others which they perceived as impossible challenges. They talked about effective self-control strategies, as well as instances where they gave in when situations were particularly difficult. For example, while they might not even consider eating cake at home and any tempting thoughts to have a piece would be easily overcome, resisting cake at a party could turn out to be an impossible task. This pattern suggests that while 'getting used to' managing diabetes generally helped to ease the difficulties of everyday management, it still left barriers, which were particularly hard to overcome. Participants in this group who reported 'getting used to' their diabetes management, spoke about the need for acceptance to reach this state.

> If you accept the fact that [diabetes] is now part of your life, then you
> get used to it. If you don't, you'll get shattered. (Harry, 60FG)

5.4.3   Property: Controlling with ease

The group of participants who fell in this category perceived little or no difficulty with managing diabetes. This group was the smallest of the three. Individuals within this group were less likely to express difficulties during interviews than others and they were generally very satisfied with the way they managed their diabetes.

Although they would admit to finding it difficult at first, their current experience was considered as different and better than that of others who fell within the other groups. For these individuals, diabetes self-management was generally not difficult and it 'did not bother' them. They almost spoke about self-management in a taken-for-granted way. Situations which were perceived as very difficult by other participants, seemed to be overcome with relative ease by individuals in this category. For example, resisting tempting situations where food was concerned, did not seem to be particularly challenging.

> I feel very satisfied [with my diabetes management]. Considering how many sweet products I used to eat, now I have reduced these drastically. Nowadays, I would go to a coffee shop, I have a coffee and I sit by the sweet counter ... like this, in front of it, and do you know what I say? ... "Blessed are those who can eat them", but I never feel tempted to have one. (Matthew, 40FG)

Participants in this group managed their diabetes in what they called 'their way.' This meant that they would plan management styles to suit their needs and preferred lifestyle. This seemed to contribute to making life with diabetes easier for this group. A case in point is how a female participant in this category would first eat her midday meal and then exercise in the afternoon to compensate for this. She timed her exercise such that she could enjoy her midday meal the way she wanted to.

> I've got used to it [managing my diabetes]. I have my own way [of managing it]. As soon as I wake up I have some cereal. After an hour or two I eat some fruit. I eat at midday and then I go for a walk. That is why I walk in the afternoon, so that I am able to eat well at MD, not that I eat much, but I eat well. (Lilian, 50FG)

Some of the participants in this group still encountered problems complained of by individuals in the other groups. For example, one of these participants talked about his problem of over-eating prior to being diagnosed with diabetes and his consequent need to drastically change his eating habits and lose weight post-diagnosis. However, rather than perceiving this as a problem, he reckoned the change he made as a great personal achievement. This illustrates how some individuals within this group would have experienced tough times when they struggled to control their diabetes, yet certain life experiences enabled them to gain the willpower they required to

manage and adjust to their condition. This way, over time, they had progressed from the category of 'struggling to control' to that of 'controlling with ease.'

It is important to note, however, that some individuals actually moved across categories in the opposite direction, whereby their experience of self-management became increasingly challenging during a particular episode in their lives. This happened, for example, when an individual's change in work conditions made it difficult for him to regularly have a snack or even take his insulin on time. This shows that over the years, while some individuals managed to progress in their self-management, others may have continued to face a certain level of difficulty, or may have even reverted to a level of increased difficulty.

5.5 Being responsible for my diabetes management

When talking about the need to achieve self-control, participants showed awareness of their need to actively participate in their care. They commented that they were constantly reminded of this by their family and friends, by the medical profession as well as through the media at large. To this extent, they regarded self-control as being an obligation or duty. The obligation to control is tied with expectations of action *and* responsibility on the part of the patient. Even participants who appeared to be amongst the least committed to achieving self-control, still thought that the responsibility for their diabetes management was their own. This observation was made when participants were specifically asked who they felt was responsible for the management of their condition. A further indication that participants felt responsible and accountable for their diabetes management was the fact that when they mismanaged or dodged responsibility, they felt guilty about having done so.

> ..that is why I feel guilty [when I am not careful]. That is why, because I am responsible for my health. I am responsible for managing my condition. So, if I am responsible for it why did I have to do wrong? [….] Because as long as you have only one [small piece of chocolate] ... that is OK, the taste is there, but when you go over the limit, I feel very guilty about that. (Sue, 60Int)

Participants were also ready to blame themselves if things went wrong, again reflecting feelings of accountability.

> I certainly do not want parts of my body to become affected by my diabetes because that would be a different story [….] I am content for now, sort of, but then [if I had to get complications], I would not be pleased, I would say that I have brought this upon myself. (Adrian, 50Int)

Despite expressing feelings of accountability for their self-management, participants seemed to fail to assume autonomy in such management and many would report being dependent on others, particularly family members, for aspects of their diabetes management. Dependency on family members was higher amongst males, but females also reported depending on their husbands for technical skills, such as insulin injections. As stated by a female participant, her husband would not just administer her injection, but also decide upon the dose or types of insulin which she was to receive.

> … even with injections, my husband [would ask] "How was your blood glucose this evening?" [I would answer] "4.5" [Then he would say] "Then now I will not give you actrapid (a fast acting type of insulin), just have insulatard (a slow acting insulin)." (Christine, 70FG)

Males, on the other hand, depended on their wives to cook the right food and to take care of their medications. In fact, when questions about medications were made during the recruitment phase, males would turn to their wives for answers. Younger participants reported a dependency on their parents for everyday tasks. For example, a male participant in his late 20s, said how his mother took care of his medications and how his father would sometimes check his blood glucose while he slept.

> I never forget to take my tablets because my mother puts them on the table [and tells me] "here they are, take them". (Frankie, 18Int)

> Sometimes [my father] checks my blood glucose while I am asleep. He would wake me up and say "come on" and he will carry out the test. [Then] he would say "Ok its fine" and then he'd go to sleep. (Frankie, 18Int)

This last section has showed that individuals with diabetes do acknowledge their responsibility for self-management. This is regardless of their ability or commitment to adhere to management recommendations and may be unrelated to their autonomy in practicing self-management tasks.

5.6   Summary of findings

This chapter presented findings related to the core category which is about participants' perceptions of diabetes self-management. This was construed to involve assuming control over mind and body such that an individual is able to meet the physical demands of his/her condition and be able to adapt to it psychologically and socially. Adaptation to diabetes is about moving on with one's life while caring for one's diabetes.

Participants were found to experience different levels of difficulty with managing their diabetes. While some struggled to self-manage, others reported becoming used to having to manage despite experiencing difficulties at times. A minority seemed to be managing with relative ease. Individuals were found to move back and forth between levels of difficulty. Despite their limitations, some individuals learnt to manage and adapt to their diabetes and in so doing they moved from experiencing difficulty with managing diabetes to managing it with ease.

The data suggests that failing to acknowledge responsibility for self-management is unlikely to be the reason why some individuals kept struggling to self-manage. In fact, the general perception was that responsibility for self-management rested with the patient.

Part 2: Discussion of findings

5.7   Introduction

This section will discuss findings related to participants' views of diabetes self-management as presented above. Discussions will draw upon literature available on this subject.   This is mostly diabetes-related literature although reference will also be made to general literature concerning specific concepts. Classical and seminal literature will be included.

This section will first discuss findings related to the expressed need for control of mind and body within self-management, followed by a discussion on the role of adaptation to one's diabetes and how this may minimise disruption of one's life when faced with chronic illness. The levels of difficulty in managing diabetes are then discussed. Levels identified in this study do not seem to be unique to the Maltese scenario and this section will compare local findings with the literature and analyse related concepts. The chapter concludes with a discussion of views about responsibility for self-management.

5.8   Holistic versus dualistic beliefs in lay definitions of self-management

In describing what diabetes self-management entails, participants mentioned various approaches to behavioural and thought management which are needed to address the physical and psychological demands of their condition. These include flexibility and planned management as well as stress management and the development of a positive mind-set towards diabetes. I have grouped these into a comprehensive 'strategy' for self-management. Although each individual element of this strategy has been addressed in other studies in relation to coping with chronic illness, the combination of these elements in a single, comprehensive strategy is new to the literature. Having originated from participant data, this strategy reflects an emic view of self-management and will consequently be referred to as an emic diabetes self-management strategy, or in brief, emic DSMS. This strategy will be discussed in detail in the following chapter. At this stage, it is important to note, that the holistic

notion about self-management as held by participants, is in line with definitions of chronic illness self-management as presented by various authors in this field and which explicate the need to cope with both physical and psychosocial responses to illness. These definitions have been briefly analysed in Chapter 2 (Section 2.3.2). The following section will compare participants' definitions with that held by other individuals with diabetes across different cultures. The idea is to explore any cultural differences between lay persons' perspectives of self-management.

The idea of exploring definitions of self-management amongst Maltese individuals with diabetes was based on evidence which shows that lay definitions may be different from those held by health providers (Fitzgerald *et al.*, 2008; Wu *et al.*, 2014). This may hinder patients from following providers' management recommendations which they may not understand or with which they may not agree (Barko *et al.*, 2011). Hence, as explained by Kleinman (1988) in his seminal work on the illness experience, in order to improve treatment outcomes, it becomes necessary to support self-management in a way which addresses patients' understanding of disease. Furthermore, lay perceptions about self-management tend to be culturally sensitive, such that learnings obtained from other cultures may not be pertinent to the Maltese scenario. For example, Hjelm *et al.*, (2005) carried out a study in Sweden amongst men of Swedish, Arabian and former Yugoslavian origin. They found that while Swedish participants referred to the importance of physical management of diabetes through adherence to dietary and medical recommendations, non-Swedes focused more on avoidance of stress and worry in their diabetes management. Similarly, Furler *et al.* (2008) in their study of an Australian multi-cultural sample, found that amongst their English speaking participants, diabetes self-management was about maintaining self-discipline and behavioural control such that life with diabetes became a matter of 'staying on top of it'. On the other hand, Turkish and Arabic speaking participants viewed self-management as a process of staying calm and maintaining an emotional balance. The divide amongst cultural groups between those who believed in looking after the 'body' and those choosing to focus on the 'mind' when managing diabetes, could be connected to differences in the perception of 'self' amongst these cultural groups.

As stated by Gomersall *et al*. (2011), different cultures are associated with particular views about the self and identity which in turn, tend to affect the way people choose to manage their illnesses. In line with dualistic beliefs, western societies are known to consider the body as a discrete entity, separate from thought and emotion (Kleinman, 1988). Although there has been a movement within western medicine to a more holistic understanding of health, there is still considerable resistance towards accepting a notion of unified mind and body (Pieri, 2008). This may explain why those pertaining to a western culture in the studies quoted above, focused on behavioural control aimed at stabilising physiological function. Many non-western societies, on the other hand, view thought and emotion as being integrated with bodily function (Kleinman, 1988). In fact, Chun and Chesla (2004), while studying cultural issues in disease management, reported that within the Chinese tradition of viewing mind and body as a single entity, the Chinese Americans in their study considered taking care of the 'mind' as important as controlling bodily functions in diabetes self-management. So did the Arab speaking participants in studies quoted above.

This divide between western and non-western notions of self and self-care has been challenged in this study. This is because despite their western culture, Maltese participants, considered control of the mind and body as important aspects of self-care, believing that while they needed to control behaviour to re-establish physiological balance, this would be difficult to accomplish if not coupled with controlling stress and adopting a positive mind-set towards having diabetes. Synchronisation of mind and body functions seemed central to their definition of self-management. Whether this non-western outlook on the 'self' is partly attributed to the historical influence of non-western cultures in Malta, such as that resulting from the Arab dominion in the past, is one explanation which could be considered. In fact, other findings will point to the unique way of how a culture based on both 'modern' western ideologies and non-western influences, such as the Maltese culture, may indeed influence self-management. Such findings will be presented in the following chapters.

As Christopher and Bickhard (2007) assert, holism extends to include connectedness of the self with the external environment. In fact, these authors explain how dualistic

patterns of thinking (as opposed to holistic patterns) tend to induce people to treat the socio-cultural environment and the person as two separate things. This tends to undermine the impact of external influences such as culture, on the internal experience of a person. Embracing the concept of holism, participants in this study spoke of how the social environment influenced their self-management and examples of this will be discussed in the following chapters. Also, in managing their diabetes, participants felt they needed to retain connectedness with their social world, through maintaining meaningful social roles. Life had to go on, with or without diabetes, and this meant addressing their social needs while managing their physical problem. For participants this meant *adapting* to diabetes while managing it, as will be discussed in the following section.

5.9   The concept of adaptation

For participants, adaptation to diabetes meant moving on with one's life while caring for their condition. This involved living up to the expectations of their roles in society (such as mother, worker or friend), despite restrictions implicit in diabetes management. For example, a male participant referred to how he would lose his friends if he did not regularly go to the pub to join them for a round of beer. This was expected of him and he had to find ways by which he would join his friends but restrict his beer intake. Participants also wanted to keep attending social activities which held personal and cultural meanings. This would include going to celebrative occasions which involve food. In relation to this, adaptation was seen as a means of maintaining normality while caring for one's illness, this being the ultimate goal for self-management. In fact, while the need of controlling oneself to manage diabetes dominated discourse of self-management, this idea of adaptation seemed to give another dimension to the concept of control. It specified the need of being 'in control of your life with diabetes' rather than allowing diabetes to 'take control over your life.'

The concept of needing to move on with life while managing chronic illness is not new in the literature. Upon exploring the experience of chronic illness, Charmaz (1983, p. 169) writes about maintaining a 'normal self' despite limitations of chronicity, as becoming the "symbol of the valued self." Morris *et al.* (2006, p.

395), studying patients with Type 1 diabetes also found that their participants wanted to 'master' their illness such that it would not dominate and take over their life, while Nguyen and Edwards (2014), found that their Vietnamese American participants, expressed the need to move forward with their lives, rather than focus only on their diabetes. Quantitative enquiries about perceptions of self-management have also reported patients' priority on maintaining normality when living with chronic illness. For example, Schiotz *et al.* (2012) studied what educational services their respondents were mostly ready to pay for and found that 'willingness to pay' was highest for acquiring the competence to live a fulfilling life with diabetes. This was higher than preventing complications and other self-management goals.

The need for striving to maintain normality when caring for chronic illness is highlighted by Kleinman (1988, p. 31) who writes about the potential of such illness to act like a sponge and "soak up personal and social significance from the world of the sick person." In his classic work on chronic illness, Bury (1982) writes about the disruption chronicity may bring to the structure of everyday life. For example, maintaining social roles and relationships may become difficult, as will trying to keep to previous plans and expectations for the future. In the face of this reality, individuals with chronic illness make attempts to normalise and disallow their illness from absorbing whatever is meaningful for them. This may not be easy. Participants in this study spoke of psychological and behavioural efforts required in this process. They spoke of the need to adopt a positive psychological response to diabetes. This involves developing the right mind-set about having this condition by trying to remain optimistic and by accepting their condition. Such a response, would in turn, fuel their motivation and ability to manage diabetes with minimal social disruption. Participants also spoke of the need for specific approaches to behavioural management, such as the use of flexibility, which would help them manage their behaviour with minimal life disruption.

The key message conveyed by participants was that mental and behavioural strategies need to be used with the aim of maintaining a fine balance between the demands of diabetes and the need to live a normal life. Paterson *et al.* (1998), upon reviewing literature on diabetes experiences in their meta-ethnography, developed this widely quoted concept of balance and adaptation. They found adaptation

(moving on with life) and management of diabetes (controlling blood sugar levels) to be simultaneous and interdependent and both necessary for the affected person to come to terms with his/her condition. In their review, the need for balance between diabetes and life demands emerged as the predominant feature of the lived experience of diabetes.

Although views of diabetes self-management were generally similar, the actual experience of such management clearly differed amongst participants. For some, this was construed more challenging than for others. This phenomenon is discussed in the next section.

5.10   Levels of difficulty with managing one's diabetes

Early on in my data collection and analysis, I learnt how individuals responded differently to diabetes, depending on how easy or difficult they found self-management to be. I came up with three levels of difficulty, ranging from 'struggling' to manage to managing diabetes with 'ease.' The levels of difficulty identified do not seem to be unique to participants in this study. Earlier qualitative work on diabetes experience, has identified similar patterns, which are sometimes referred to as patterns of 'coping' (Kelleher, 1988; Maclean, 1991; Hernandez, 1996; Rayman & Ellison, 2004). As Campbell *et al*. (2003) point out, these similarities across studies may show that individuals' response to diabetes self-management takes a form of 'patterning' which may be common amongst individuals living in different cultures. The patterns identified in this present study are particularly similar to those reported by Kelleher (1988), whose work in this area has been considered as classic (Campbell *et al.*, 2003). Kelleher (1988) conducted interviews with thirty individuals living in London and organised their diabetes experiences into three categories which will be compared with the three categories presented in this study. Despite similarities with other studies, this present study has contributed information about characteristics of individuals who experience particular levels of difficulty, which is new to the literature. While helping to extend the literature on this subject, this may point to cultural issues underpinning these varied experiences. Patterns of coping, as identified in this study, will be discussed with reference to related literature below.

Individuals in this study, who were seen as 'struggling' to achieve self-control seemed to correspond to those identified and referred to by Kelleher (1988, p. 150) as "worriers and agonisers" whose response to diabetes was dominated by worry, poor acceptance of their condition and lack of confidence to manage it. Corresponding individuals of this present study reported similar responses to those identified by Kelleher (1988), but they often attributed these to being overwhelmed by change. These participants, who often called themselves 'food lovers' saw the required change in their lifestyle as 'drastic,' 'complete' and impossible to actuate. This tended to create a tension between what they felt they should do and that which they experienced as possible to accomplish. In fact, failing to actuate dietary change amongst these individuals, tended to communicate a sense of 'powerlessness' over food. This overwhelming sense of difficulty with controlling food may have cultural connotations, which will be explored further in Chapter 7. In fact, significant problems experienced by Maltese individuals with diabetes in controlling food intake, has been documented as early as the beginning of the 19th century where patients were noted to be "quite willing to take 'tablets' and 'injections,' but were very reluctant to follow the prescribed dietary regime" (Cassar, 1982, p. 19).

Feelings of failure amongst individuals who struggled to self-manage were not only associated with failing to actuate change, but also with failing to control blood glucose *despite* having changed one's behaviours. This transmitted a sense of frustration which culminated every time blood glucose results were higher than expected. Studies have shown how experiences like these may, in fact, lead individuals to abandon their dietary regimes (Peel *et al*., 2004; Peel *et al*., 2007). Overall, feelings of powerless over food and of being a failure seemed to result in developing poor confidence in one's ability to self-manage. This is highly related to poor self-efficacy, which has been found to adversely influence how much effort is placed on performing a task in the face of difficulty (Bandura & Shunk, 1981). The implications of this on self-management could be significant.

When allocating participants in groups according to their perceived level of difficulty with managing diabetes, the largest group was composed of those who found self-management 'moderately' difficult. These seemed to be getting used to living with and managing their condition, despite various difficulties which they

experienced, but which they seemed to downplay. These participants learnt to overcome some of the challenges of living with diabetes, starting to perceive these as 'less burdensome,' but found other challenges impossible to overcome. As a result, their behaviour fluctuated between periods of adherence and periods of poor levels of self-management. Compared to those who struggled to self-manage, these individuals would not consistently complain of needing to change their lifestyle but at the same time would not report particular effort to try and adapt behavioural change to their preferred way of living. This group compared well with the group of participants which Kelleher (1988) referred to as adapting to diabetes through the process of 'normalising.' Normalisers in Kelleher's (1988) study were those who were not high in self-control, but accepted their symptoms and played down the significance of changes they had to make.

Finally, participants who perceived least difficulty with managing diabetes were those who reported to manage their condition 'their way.' These demonstrated less difficulty with maintaining behavioural change than participants in the other groups. They demonstrated a tendency to be flexible and adapt their diabetes management to their specific needs and preferences, hence their reference to manage diabetes 'their way.' In contrast to those who struggled, participants in this group were generally satisfied with the way they managed their diabetes. This group compared well to those which Kelleher called 'copers' in his study. Copers were high in control of their diabetes, they were flexible and adapted to diabetes such that they would preserve their work and social life.

As in other studies (Price, 1993; Hernandez, 1996; Rayman & Ellison, 2004), participants in this study were found to move from a difficult level experienced during initial stages of their condition, to one less difficult, along the years. This was evident by the way participants who 'got used to' managing their diabetes and those who managed it 'with ease' referred to how they required time to get to their present stage. Rayman and Ellison (2004) associated this movement along the 'difficult-easy' continuum, with a process of learning how to self-manage. I will also be referring to this as the process of learning how to cope. This process has generally been found to involve the adoption of flexibility in one's approach to self-management, such that, as was found in this study, those who report least difficulty

with self-managing would have learnt to adapt diabetes-related behaviour to their specific needs. This issue will be discussed in greater detail in the next chapter.

Important to note was the fact that 'learning' to self-manage was not achieved by all, and for a number of participants, struggling to self-manage became the norm. However, factors which made life with diabetes difficult for those who struggled, such as needing to make drastic changes, would have been experienced by those who still managed to move on to a stage where they managed with ease. Furthermore, some individuals were also found to revert back to more difficult stages at times when life situations changed during their life course. These observations show that movement along the different levels of difficulty is not automatic, but may indeed be related to socio-environmental factors which may determine the direction of such movement. Once this finding came to light, movement along these phases of difficulty became considered as the basic social process which would underpin my theory. The aim of my data collection and analyses then became that of exploring what affected movement of participants along the continuum, or indeed, what caused some of them to get stuck within levels of high difficulty. This aim guided my theoretical sampling. Related findings will be presented and discussed in Chapters 7 and 8.

The sections above have discussed major concepts emerging from data analysis in terms of what self-management was seen to involve and how easy or difficult it was perceived to be. The last section will address responsibility for self-management which is an overarching concept addressing how participants' meanings could have been influenced by societal values regarding health.

5.11 Responsibility for diabetes self-management

The issue of responsibility for self-management amongst adults with diabetes has not received much attention amongst researchers, even though, poor self-management has been associated with a poor sense of responsibility amongst young individuals with this condition (Anderson & Laffel, 1997; Schilling *et al*., 2006). Hanna and Decker (2010) analysed the concept of responsibility for diabetes self-management, drawing upon empirical and theoretical literature on responsibility amongst

adolescents with diabetes. The authors associated this phenomenon with 'ownership' of one's condition. Ownership, according to the analysis performed, involves autonomy or independence in diabetes behaviours and decision making. Applying this view of 'ownership' to participants in this study was problematic, since feelings of responsibility and the practice of autonomy did not seem to coincide amongst participants. This will be discussed below.

Participants, in general, viewed and reported diabetes management as their responsibility, as though they 'owned' it, such that they felt accountable for disease outcomes and blamed themselves when things went wrong. At the same time, however, some of these individuals reported depending on others, such as family members for aspects of self-management. Overall, it seemed as though while family fostered dependence as a way of supporting their loved ones, in doing so, it hindered autonomy in diabetes management. Participants also reported being wholly dependent on health professionals on decisions regarding their diabetes management. They said they were not given the opportunity to discuss such management during consultations. Reliance on others for aspects of diabetes management reflected a cultural climate that promotes dependency, this being experienced within different social organisations, such as family and healthcare. Chapters 7 and 8 will analyse participants' relationships with family and health professionals, shedding further light on this subject.

As shown in the section above, whether for participants, dependence was forced or welcomed, their ideas of ownership did not correspond with practices of autonomy. Hanna and Decker (2010) write how ownership of self-management and practiced autonomy depend on two factors, namely expectations of responsibility by the person, or by others and interaction with others. As indicated above, interactions with health professionals and family were seen to be unsupportive of autonomy at times. The issue of expectations of responsibility will be discussed below.

Broom and Whittaker (2004) write about modern society's views regarding responsibility towards one's health. They refer to how, in contemporary culture, people are expected to assume control over themselves, as this confers health benefits. Being in control is associated with power and agency and is considered as

a means of overcoming threats to one's health. As Parry *et al.* (2006) point out, this is especially so, considering the widely held view that chronic diseases are, to a large extent, preventable and controllable. Thus, being 'in control' to retain or regain health, becomes highly valued. It is viewed as one's responsibility and moral obligation. This understanding is intensified in diabetes, where, as highlighted by participants in this study, assuming control over oneself is needed to maintain control of blood sugar. Thus, as mentioned by Broom and Whittaker (2004, p. 2381), frequent references to control form part of the "moral discourse surrounding diabetes." This is reflected in expectations of compliance to treatment from the public, who view failure to comply as a moral failure and who are thus, only too ready to judge and stigmatise non-compliance.

These arguments may support the idea that participants' views about being responsible for their diabetes management are a reflection of public expectations and that they are socially constructed. In fact, participants often referred to experiencing or anticipating judgemental reactions to their non-adherent behaviour. A sense of morality attached to responsibility, is in turn supported by participants' use of moral terms in their discourse of self-management. Participants sometimes referred to their non-adherent behaviour as 'sinning,' this being a conventional way of expressing 'shameful' behaviour in a strongly Catholic society, such as the Maltese society. Sinning and shame may also be attributed to the fact that for Catholics, their body is a sacred gift from God and they need to take care of it as best as they can.

Admitting to a sense of guilt when failing to adhere to recommended regimens, also has moral connotations. Baumeister *et al.* (1994) refer to guilt as being socially induced, in that individuals tend to feel guilty when their actions go against social standards. In fact, these authors argue that showing disapproval is a social weapon used to manipulate the behaviour of others, through instigating feelings of guilt. Since guilt in itself is emotionally distressing and because it denotes potential social exclusion, individuals seek to avoid it through being pro-social in their behaviour; that is, by acting according to social expectations (Baumeister *et al.*, 1994). These arguments have relevance to this study. They may imply that social interactions did not only cultivate thoughts of self-responsibility, but were also involved with instilling feelings of guilt related to such thoughts.

The sections above have highlighted the fact that a sense of responsibility for self-management may indeed be socially constructed and intensified through connections with beliefs of moral obligation. Gomersall *et al.* (2011) refer to these assumptions of personal accountability in diabetes self-management as denoting an individualistic point of view, whereby responsibility for self-management is seen to rest *solely* with patients themselves. The authors make a note of caution with regards to these assumptions. These tend to undermine the potential influence of contextual factors on self-management which may indeed work against individual effort to achieve control or independence in self-management. For example, earlier in this section reference was made as to how relationships with family and health professionals may threaten autonomy and foster dependency. Therefore, going back to the concept of 'ownership,' as described by Hanna and Decker (2010), it seems that while participants declared such ownership in self-management, they faced problems with assuming the autonomy that goes with it. Both the idea of 'ownership' and the challenges faced with living up to it may stem from within social structures. Thus, as stated by Gomersall *et al.* (2011), shifting responsibility for health from the state to the individual wrongly assumes that people have knowledge and above all, real choices for health behaviour. The implication is that social context, may indeed play an important, or even central role in self-management. This will be discussed further in the chapters which follow.

5.12   Conclusion

This chapter has analysed participants' views of diabetes self-management, this analysis being viewed as pivotal to understanding ways in which such management could be supported. Participants' definition of self-management embraced a holistic vision of self. There is reason to believe that these views emerged from their experience of diabetes, which led them to realise that controlling their body while ignoring their thoughts about diabetes, was unhelpful. This was exemplified in their failing efforts to manage their diabetes when stressed. Comparing participants' definition with those obtained in other studies seemed to challenge the idea that holistic understandings of self-management are more common amongst non-western societies. This has shed light onto how the Maltese culture, which is considered to

be essentially western, may indeed be associated with unique beliefs and experiences of diabetes, which are atypical of other western communities.

Participants also felt that managing diabetes could not take precedence over maintaining social roles. This would risk social exclusion and abandoning meaningful social activities. Thus, they spoke of adapting, rather than simply managing their condition, a notion which is highly supported by literature on the experience of chronic illness. In order to manage their condition holistically, participants came up with skills which they needed to develop in order to manage their thoughts and behaviour and these included flexibility, planned management, stress management and developing a positive mind-set towards diabetes. The idea of integrating these skills into a strategy for self-management has not been traced in the literature. This 'emic' strategy, emerging from participant data (referred to as emic DSMS), will be discussed in detail in the next chapter.

Despite agreeing on what constitutes self-management and discussing the way forward towards achieving their goal of adaptation, participants perceived varied levels of difficulty in achieving this goal. This highlighted the extent by which participants' experience and response to their diabetes varied across the group. Three levels of difficulty were identified and these followed a pattern which was similar to that identified elsewhere, ranging from 'struggling' to manage to managing 'with ease.' Individuals were found to move across these levels in their life-course and the literature refers to this movement as the process of learning how to self-manage, whereby individuals move from a high to a low level of perceived difficulty. However, in this study, such movement was found to go in both directions, such that individuals were found to progress and at times regress in their management skills. This movement across the coping continuum represents the basic social process of this study.

An important concept emerging from participants' views of self-management was that of responsibility for such management, which participants perceived as being their own. These views seemed to stem from societal norms which push the idea that individuals should assume control over the self to look after one's health. These have been labelled by Gomersall *et al.* (2011) as highly individualistic views which

undermine the influence of context on self-management. In fact, while valuing responsibility and ownership, participants seemed to struggle to achieve the autonomy which goes with it and this may be partly associated with everyday interactions which fostered dependency. It seems, therefore, that while society may be expecting individuals to assume responsibility for self-management and to look after their health, underlying cultural trends may be failing to support related behaviour. This phenomenon will be analysed further in the forthcoming chapters.

The next chapter will examine the nature and outcomes of participants' successes and failures in implementing the strategy for self-management which they came up with. Following that, Chapters 7 and 8 will examine factors which may have influenced these successes or failures and which may, in the process, have determined participants' position or movement across the coping continuum.

Chapter 6

CATEGORY 2:
MANAGING MY THOUGHTS AND BEHAVIOUR

Part 1: Findings

6.1   Introduction

The previous chapter introduced the self-management strategy which participants came up with when discussing what diabetes self-management meant to them. This involved thought and behavioural management and is being referred to as an emic DSMS. This chapter will focus on how effectively participants applied elements of this strategy in their everyday life.   The chapter will also examine how the application of this strategy, or failure of such application, influenced participants' coping with diabetes, as determined by the position they assumed within the difficult-easy continuum, described in the previous chapter.

The category examined in this chapter consists of two subcategories and their properties, which will be presented and described in the sections which follow. The first subcategory outlines how participants managed their behaviour in relation to their diabetes, and the second subcategory addresses how they processed their thoughts about their condition. The elements of this category are represented in Figure 6.1 which also serves as a diagrammatic representation of the emic DSMS.
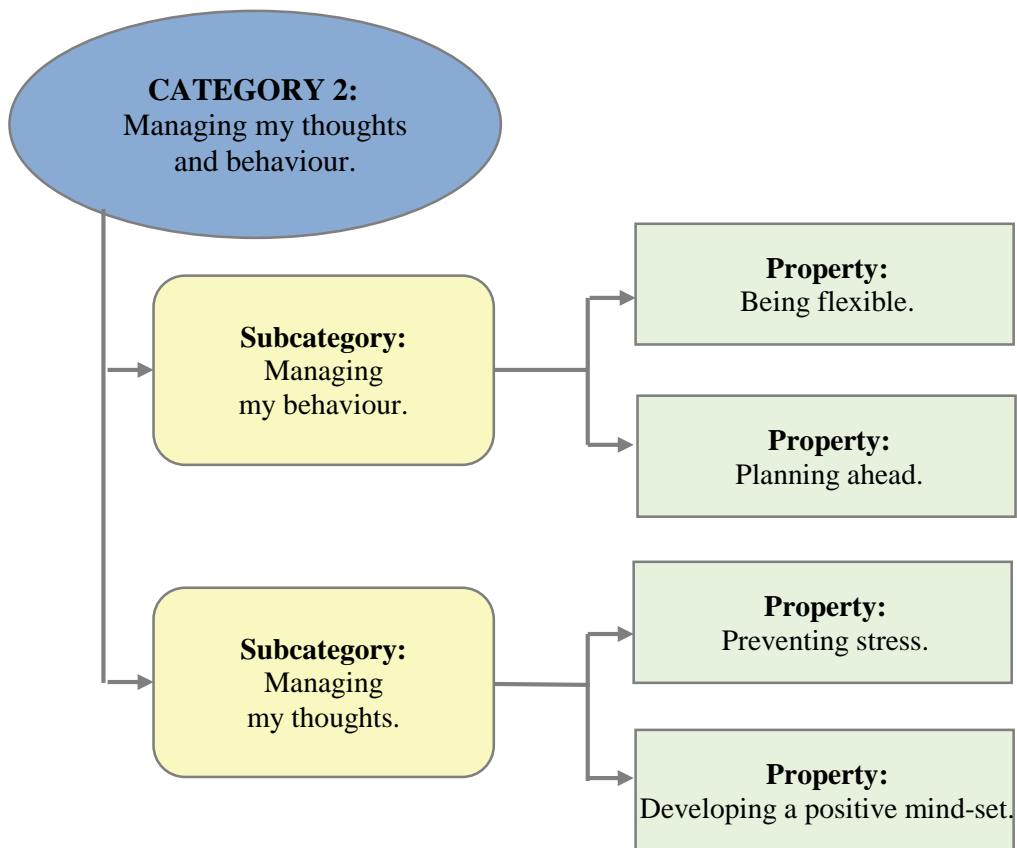
Figure 6.1: Elements of Category 2 including related subcategories and properties

6.2 Subcategory: Managing my behaviour

This section will focus on two general approaches to behavioural management, which participants construed to be crucial in helping them manage their condition successfully; flexibility and planned or strategic management. Both of these will be presented as properties of this subcategory. This section will explore the extent to which participants succeeded to apply these approaches in their everyday management of diabetes.

6.2.1 Property: Being flexible

For participants, flexibility in management meant adjusting one's behaviour to suit his/her everyday needs or preferences, whilst remaining generally loyal to the principles of diabetes care. Participants viewed flexibility as being key to successful

management of diabetes as it helped them lead a normal, socially fulfilling life, while managing their condition. That is, it was perceived as central to helping them *adapt* to their diabetes. Individuals who failed to adopt a flexible approach were considered as being rigid and unyielding to diabetes recommendations, failing to assume a practical approach to management.

A number of participants mentioned how they successfully applied flexibility into their dietary management and chose not to deprive themselves completely of restricted food, such as chocolate or alcohol, but to eat/drink them in moderation. In the process they would often adjust other behaviours to maintain a balance in their blood glucose level. This helped them satisfy their desire for a particular food item and allowed them to participate in social activities involving food or drink, such as eating out and going to parties or pubs.

> For example, when we eat out, there would be sweet desserts. My wife would take a portion and I would also take a piece, not too much, but just to taste it. I would take a [small] piece like this, so just to keep in synch with everyone else. (Luke, 50Int)

Participating in social activities was often brought up by participants, because these occasions proved challenging for those who found it difficult to control what to eat in a food-rich environment. Those who failed to be reasonably flexible and eat in moderation would either go to the occasion and 'forget' about their diabetes, or opt not to go to such social events altogether. The latter meant being an outcast, as the following participant pointed out.

> If you set yourself a certain level of control and say, "This I won't take, and that neither, and neither that, and there I won't go, and there maybe…" I think you will be turning yourself into an *outcast*. The first thing is that you stop going to parties and you won't go here or there…even your face will start to register [a sense of depletion]. I am intentionally exaggerating here. (Roderick, 60 FG)

An example of a rigid approach to management and lacking in flexibility is featured in the following excerpt from a male participant who reported his diabetes self-management as being 'very difficult.'

When I get invited to a wedding, I tell [my wife] "I'd better not go" [….] and I don't! I would go only when it is of a close relative [….] I stay there, I grab a sandwich and something else, but nothing more, not even an ice cream or half a sweet pastry. I swear to you, I have been ill for thirty-three years and that is how long it has been since I have eaten a sweet pastry. (Leonard, 60FG)

Being reasonably flexible with timing of medications was also considered important to adapt to diabetes in everyday life. Individuals spoke about adjusting timing of medications, such as insulin, to suit their work requirements. Although newer forms of insulin medication, such as insulin analogues, enhance better flexibility, these types of medications were not easily accessible to participants in this study and this will be addressed in more detail in Chapter 8. Since flexibility facilitated adaptation to diabetes, individuals who were flexible were more likely to report their management as 'easy' and to react positively to having diabetes, stating for example, that they got used to it, that it did not bother them, and that they were satisfied with the way they managed it.

Individuals who were flexible used strategic skills to try and maintain a desirable level of blood glucose, while enjoying preferred food. This would sometimes involve working around or even 'bending' the rules of dietary regimes to some extent. A few mentioned forms of carbohydrate exchange procedures, such as selecting foods low in carbohydrate at a party to enjoy some sweet delicacies at the end. Others, on the other hand, would do extra exercise after having had a moderate portion of carbohydrate food or sugary dessert.

Sometimes I say to myself "It does not matter that I had an extra piece of bread; tonight I will go for an hour of aerobics." (Claire, 50FG)

A male participant who loved to have pizza when eating out, went through a phase of checking his blood glucose after eating pizza to see what portion he could have without going into hyperglycaemia. He therefore found a way to enjoy pizza without feeling guilty. Participants believed that carrying out such strategies would help them adjust to their preferred lifestyles with minimal impact on their blood sugar levels.

Some individuals took the flexible measures mentioned above, to extremes. Rather than bending the rules in a moderate fashion, they would indulge in restricted food, which then required drastic measures to make up for their behaviour. Nevertheless, this would still be carried out in a strategic fashion. They were often aware that this behaviour was not ideal. However, on certain occasions, finding self-control with the intake of food difficult they would choose between two evils, either by indulging in a haphazard fashion or in a 'calculated' way. One participant referred to this approach as 'cheating' his way through management, hence my choice of term 'deliberate cheating' to refer to this behaviour and to differentiate it from flexible behaviour used with moderation. Participants who deliberately cheated joked about this strategy during focus groups, sharing ideas of how one could 'cheat' and enjoy a festive occasion to the full. One of the commonest ways by which individuals 'deliberately cheated' was by having extra hypoglycaemic tablets before going to parties. They would then 'forget' about their diabetes during the party.

> I enjoy eating [during a celebrative occasion]. Yes, I do eat [a lot]. I take an extra couple of tablets before the occasion, and the day after, my blood glucose will not be high. (Peter, 60FG)

On the other hand, if individuals planned to binge drink on an occasion, they intentionally missed their diabetes tablets to prevent a hypoglycaemic attack, since alcohol may lower the level of blood glucose. Deliberate cheating was common amongst individuals who found it 'moderately' difficult to self-manage and who were inconsistent in their management, reporting times when they remained in control and others when they would simply let go. These were in the middle stage of the coping continuum (see Section 5.4.2). Those who were flexible spoke of another strategy they used, which seemed to help them retain control when applying flexibility. This is described in the section below.

6.2.2   Property: Planning ahead

Participants who found it 'easy' to manage their diabetes were more likely to report an ability to plan ahead, in a way which helped them to remain in control of their behaviour and retain moderation when being flexible. Planning ahead or proactive

management featured deliberate ways by which individuals tried to prevent the need or temptation to bend the rules of management unnecessarily or in exaggeration. For example, individuals would eat something healthy before going to a party, where the temptation to indulge in restricted food would be difficult to resist. They would rather go to these occasions with a 'full' stomach so they would be able to control what they ate there. Others kept a healthy snack in the refrigerator for when they were very hungry, such as when they came back from work. A male participant kept extra tablets in his locker at work so that if he had to work late, he would not have to skip or delay his evening dose. These strategies seemed to make it easier for individuals to manage their behaviour during challenging situations. The following excerpt from a teacher is another example.

> Maintaining control [of what I eat] at work is sometimes problematic. They sell so many delicious things at the school tuck shop and you could smell the great aroma of baking from the oven. [….]. Sometimes I would be supervising in the tuck shop...just imagine all those children buying [delicious food] and that smell!! So I would quickly eat my salad before going there, to make sure I would definitely not [give in to the temptation]. (Anne, 50Int)

Various ways of managing or mismanaging diabetes were mentioned but flexibility and planned management seemed to single out individuals who found that behavioural management of their condition was not such a daunting task, these being classified in the group who managed 'with ease' within the coping continuum (see Section 5.4.3). Figure 6.2 represents participants' varied ways in which they managed their diabetes related behaviour.
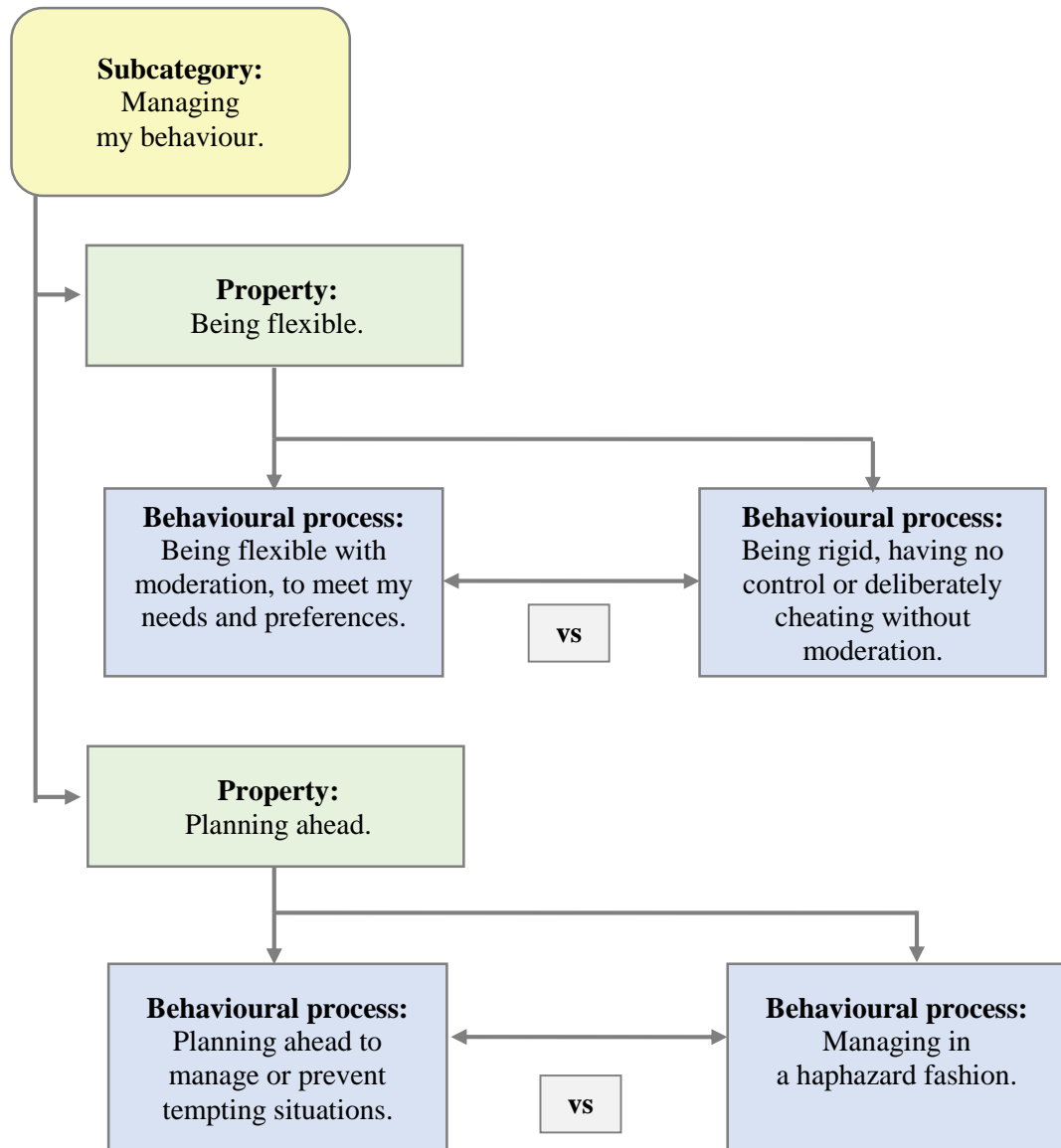
Figure 6.2 Participants' varied approach to managing their diabetes-related behaviour

Individuals did not only vary in their abilities to manage behavioural requirements of diabetes, but they also differed in their ability to respond to the psychological demands of this condition. This is described in the next section.

6.3   Subcategory: Managing my thoughts

This subcategory is about participants' ability to manage their thoughts in a way which they deemed helpful towards their diabetes management. As mentioned in the previous chapter, for participants, managing their thoughts about diabetes meant

reducing stress and adopting a positive mind-set towards their condition. The first and second property of this subcategory presents participants' experiences related to these two approaches towards thought management. Again, these properties will reveal stories of successful, as well as unsuccessful management.

6.3.1 Property: Preventing stress

Preventing stress was construed important as stress deprived participants of the will power they needed to manage behaviour. Though preventing stress related to everyday life often proved challenging, some participants spoke of successful thoughtful strategies they had used in this respect. For example, a male participant who held a managerial position, reported how since having been diagnosed with diabetes, he has had to be extra careful how to handle situations involving conflict, since this is a major source of stress. However, participants spoke mainly of how they tried to avoid stress caused by having diabetes. Many described how an endless array of issues related to diabetes would haunt their mind if they allowed them to. Therefore, interviews included talk such as 'not placing diabetes at the top of my mind,' 'not thinking too much about my diabetes,' 'not focusing solely on my diabetes' and 'not being obsessed by my diabetes management.' When striving not to allow diabetes to dominate their thoughts, individuals tried to find a middle road between being obsessed or negligent about diabetes management, with the midpoint being 'staying careful.' The excerpt below shows how a male participant rejected the idea of being extremely stringent to the point of becoming obsessive.

> Speaking about myself, I know that I have diabetes, but I am not focused on it, [I am] normal, I want to live a normal life […] I am not obsessed, I do not want to be obsessed, no I am not obsessed, [but] I am careful, yes. (Leonard, 60FG)

Finding a balance between obsession and negligence was not always successfully achieved. Individuals spoke of being negligent and they would feel dissatisfied about their mismanagement. At the other extreme, becoming obsessed with diabetes management was also perceived as stressful. The excerpt below from Tom shows how individuals could become obsessed about their management. Tom reported very frequent testing of blood glucose and frequent exercise to lower his blood

glucose whenever this got higher than normal. He would do this besides his seven kilometre daily jog. His life became dominated by calculating, testing and doing whatever it took to get his blood sugar to normal limits. The excerpt below shows only one small episode of testing and retesting which he mentioned. Tom held high expectations of his diabetes management and would feel very guilty after having been tempted to eat excessively. Perhaps, it was this same obsession which led Tom to binging episodes, resulting in further resentment.

> I might have an apple and a banana together, I would test my blood and find it 10. Now I would have actually tested my blood just before and it would have been 5, 6. Then, after some time I would go for a walk again. I would not go for a very long one, I would walk say for 15mins, and I would not run. Then, I would go back, have a shower, test my blood again, and find it normal. (Tom, 50FG)

Participants mentioned other diabetes-related experiences which provoked stress, and about which they felt unable to subdue their apprehension. By far, the most common source of stress was fear of complications. Thoughts of becoming blind, or of having parts of the body 'chopped off' were said to be 'always at the back of my mind.' The associated disability and altered body image led participants to refer to amputations as being their 'worst nightmare.' Knowing that the risk for complications increases with age, participants talked about being apprehensive about their future as they anticipated bad times.

> You do worry, because I have to think about the future, not the present … the future and what could happen then. (Lisa, 40Int)

Fear of diabetes complications was sometimes said to be a motivator for behavioral control. However, the stress it invoked still made diabetes management a dreaded and difficult task for those who allowed related fears to dominate their thoughts.

6.3.2   Property: Developing a positive mind-set

Developing a positive mind-set about diabetes was thought to help individuals adapt to a life with this condition. It was construed to involve two dimensions of thought

management, namely positive thinking and accepting diabetes. Related findings will be presented below.

There were various ways by which participants practised positive thinking. For example, some participants acknowledged advantages of having diabetes and noted improvements in their health or health behaviour since their diagnosis.

> I used to play football, and then when I grew older there was a time when I [had] stopped playing football, I stopped doing exercise. [Now] I [have] started going for walks. Diabetes made me become fit again and walk, and do sport activities which my age permits me to do [….] If I did not have diabetes I would just sit in front of my computer…(Luke, 50Int)

As mentioned in the previous chapter, the most common approach to positive thinking was that of comparing one's situations with worst case scenarios. Yet, others chose to focus on good results or positive information given during a follow-up visit, rather than dwell on bad news.

> I was shocked [on being prescribed insulin]. The first couple of days, I felt shocked […] but I always see the positive [side to things], in the sense that I say…. [the doctor] found my feet and my eyes *100% very good, thank God.* So at least I have not done any damage to those. (Lorraine, 50FG)

However, some participants found it difficult to manage their thoughts about diabetes this way. For example, a female participant described her frustrations in trying to maintain a positive outlook on having diabetes, a situation which became loaded with ambivalence, as the excerpt below reveals.

> I realise that since I have had diabetes, *I have become more emotional, more depressed,* I don't know why, I cannot explain it, because, *at the end of the day* it is nothing compared to other illnesses in the world. But I say to myself *"Why me?* Why did it have to happen to me?" But then, on the other hand I say, "Its better like this, than having it worse." You know, sort of, you cannot … part of me says one thing, part of me says another. (Nadine, 50FG)

In view of the challenges which positive thinking provided, a good number of individuals dwelled on negative aspects related to their condition. Some conveyed

feeling significantly compromised because of their diabetes and perceived themselves as being highly restricted. In their eyes, diabetes denied them the freedom to choose what to do in their everyday life, whether this related to their choice of food or other preferred activity. For example, a male participant said he had to quit his favourite sport because it increased his risk of injuries which would now take longer to heal. He also had to be extra careful when going to the beach, not to hurt his feet and this compromised the fun factor of this popular local activity. Reference was made to feeling like a 'prisoner' in one's own body and the idea of needing to restrict oneself was felt to be always at the back of one's mind.

> For me, living with diabetes involves restrictions. Sort of, part of your life becomes restricted because you cannot do what you want, you cannot eat what you want, you have to be careful [about what you do]. You have to keep it in your mind that you need to be careful. (Sue, 60Int)

What seemed to bother individuals most was the fact that diabetes-imposed restrictions were ever-present. Diabetes afforded no breaks, no timeouts. To this extent, it was also associated with lifetime deprivation.

> When you learn that you have diabetes, you get a shock, because you know that you will be deprived of what you like for the rest of your life. (Marthese, 50FG)

The idea of lifetime deprivation instilled feelings of being different. The issue of *always* having to be careful distinguished individuals with diabetes from others without diabetes who wanted to lead a healthy lifestyle. The latter could still opt to have an occasional break and indulge in a sugary treat, but this was not an option for those with diabetes. This is what made them different.

> Besides being deprived because of my diabetes, I feel *I am not a normal person anymore* […] *I am not free as I was before,* so *there is nothing positive about it*, nothing. I could go on the world's biggest weight loss programme and it could give me the most beautiful *shape*, and then someone who also went on a diet and has the same *shape* and *figure* like mine, would come near me and eat a chocolate there, beside me, and I cannot eat it! So *there is nothing positive about it*. [….] *I am not free*

anymore. This is something which breaks you. When you deprive someone of his freedom, you break him. (Alfred, 40FG)

As shown in the excerpt above, feeling different upon being restricted left some individuals little opportunity to feel good about themselves. They felt unlucky, as they scrutinised themselves in relation to other individuals, whose life, compared to theirs, seemed to be 'a piece of cake.' Managing to adopt positive or negative thoughts about their diabetes seemed to ultimately determine the extent by which participants accepted their condition.

Accepting diabetes was considered a prerequisite to adjusting to the condition and managing it with ease, as indicated in the previous chapter. As mentioned above, individuals who managed to adopt helpful mental strategies were likely to talk about accepting their condition and getting used to managing it. They would 'not mind' having diabetes and were not highly affected by it.

Once I had accepted what I have and controlled it, it no longer affected me. (Matthew, 40FG)

Some individuals seemed to have a hard time accepting their diabetes. This became evident either when they projected anger towards having the condition or when they acknowledged their inclination to deny it. Anger seemed to be the result of negative psychological reactions mentioned in the sections above. Individuals felt angry because they felt restricted, different and victimised, as a result of having diabetes. This made it exceptionally difficult for them to accept their situation. While for some, this phase might have passed and lead to acceptance, others were baffled about the fact that anger still burnt inside them, even years after diagnosis.

Even though so much time has gone by, sometimes I feel a certain rage, sort of I do not accept it. I tell myself "My God how depressing!" (Janet, 70Int)

Asked to explain his feelings of anger, a male participant gave the following account, making reference to the limitations imposed by his condition, which left

him dragging behind others when it came to life accomplishments. This seemed to crush him and he hit back through his anger.

> Sort of, *why me*? […] You feel like your *lifestyle* is getting increasingly limited by the day. We mentioned sex, we mentioned fatigue, we have not mentioned one other thing as we have focused on food and control - there is exercise which is very important […] Now as we are firing like a machine gun about food *bla bla bla*, you have exercise as well and you end up [saying], "My God, everyone around me is ready to go for the Olympic Games except for me…why am I feeling so lethargic?" Do you understand what I mean? It starts like… first you are hit by words, then [the impact] gets bigger and they become like walls which you feel are crushing upon you *and you start hitting back*. That is the anger [I feel]! (Roderick, 60FG)

Being badly hit by the news of having diabetes, some individuals conveyed resorting to a psychological measure which seemed to push back the immediate need to act upon their diagnosis: denial. Some participants denied diabetes because their blood glucose levels were always near to normal. Deranged blood glucose results also gave leeway to denial when they presented no symptoms. Some individuals remained in denial years after their diagnosis. They expressed denial in different ways, such as by thinking they were simply 'prone' to diabetes or that their diabetes was not real, or had not yet been fully 'established.'

> Maybe, in my case, I do not consider myself as a pure diabetic, sort of, I am still not part of the list of those who are called *real* diabetics. (Adrian, 50Int)

A few individuals acknowledged denial as unhelpful towards managing their condition. For example, a male participant referred to his denial as a mechanism which he used in order to protect himself from becoming anxious about mismanagement. Believing that he was simply 'prone' to the condition, he convinced himself that his diabetes was something which could be 'handled in the future.' Later on in the interview, he admitted that he was actually 'kidding himself' as he was aware that this was simply a psychological game he was playing.

Obviously, if I [believe] that I am prone, I put my mind at rest. [I say to myself] *"No problem, it is something that I can handle in the future." I am pushing it back, I am pushing it back*, which is a wrong thing, because at the end of the day it is a condition. I was *prone* once, but now I have become *fully-fledged.* (Daniel, 40Int)

Whether denial came as a result of mismanagement or whether it actually led to it, individuals in denial expressed difficulty with adhering to self-management recommendations. They felt that, being symptomless, they could still afford to 'play around' with their management or take diabetes 'as a joke.' A number of participants reported reasoning this way until they experienced a turning point, whereby they suddenly realised they could no longer remain in denial. This was when they came across a 'sign,' such as when their blood glucose level rose, when they were put on insulin or when they started to feel symptoms. This is when they realised that they had to 'work' on their diabetes.

It did not dawn on me that I am a real diabetic, even though I was having tablets. [….] Now [that I have been put on insulin] it really rang a bell that I am diabetic […] I want to get [my blood sugar] down. Now I want to work on it. (Lorraine, 50Int)

Overall, those participants who experienced negative psychological reactions to diabetes and were unable to accept it, were more likely to report their diabetes management as 'difficult.' They were more likely to be classified in the 'struggling' group within the coping continuum. However, these patterns of reactions to diabetes were not always straight forward and negative cases were identified. For example, a participant amongst those who managed 'with ease' also reported negative psychological responses, such as feeling restricted by diabetes. Other participants within this group reported worrying about diabetes complications. However, negative feelings amongst the group who managed 'with ease' were not as common and generally not as strong as those of others who ended up rejecting their diagnosis and struggling to self-manage. Figure 6.3 represents participants' varied ways by which they managed their diabetes-related thoughts.
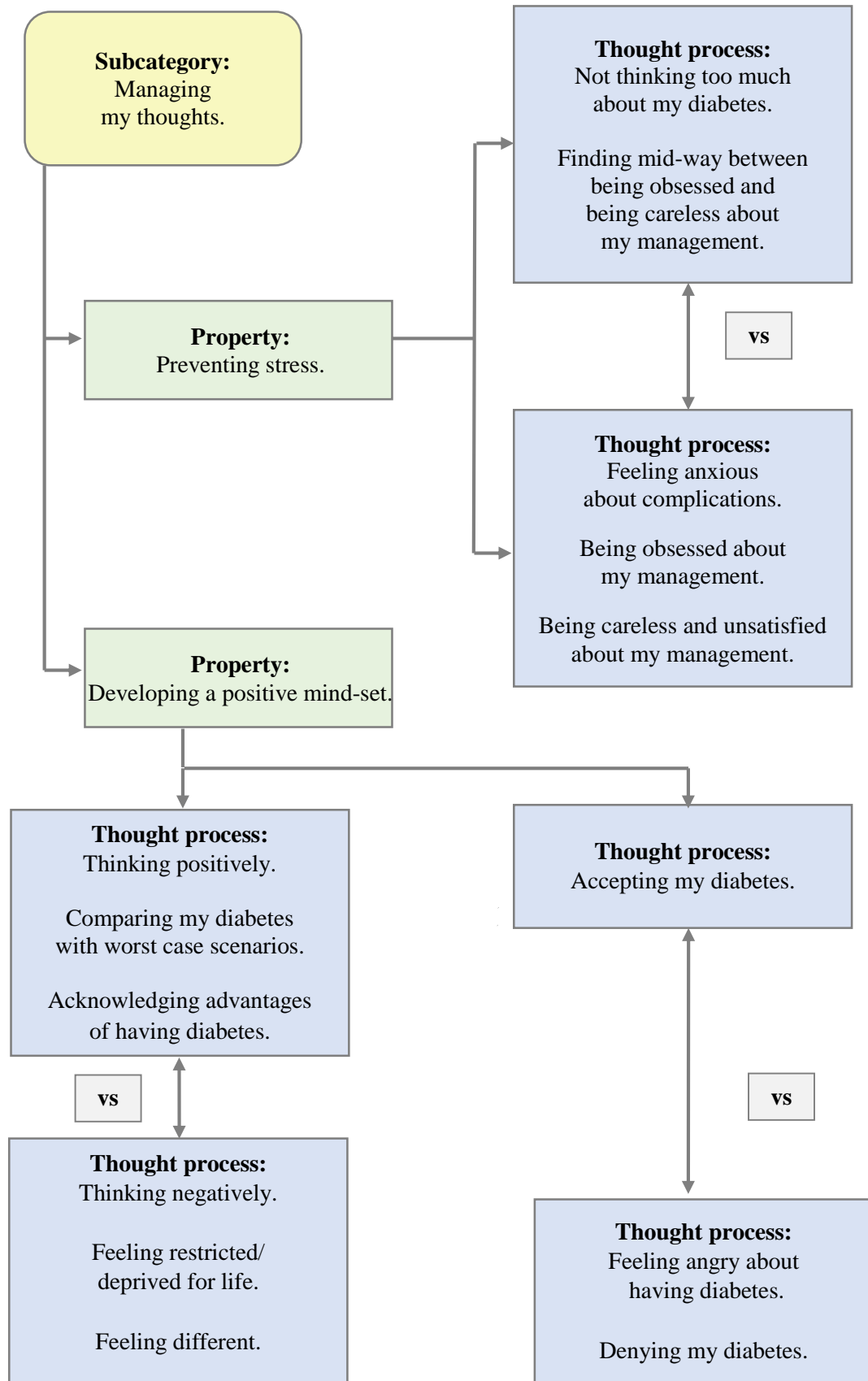
Figure 6.3: Ways in which participants managed their thoughts about their diabetes

6.4   Summary of findings

The findings showed how individuals varied in how they managed their behaviours and thoughts in relation to diabetes, featuring positive and not so positive ways of responding to diabetes behaviorally and psychologically. These responses seemed to be associated with participants' general coping with diabetes, that is, they were linked to the level of perceived difficulty when managing their condition.

Behavioural control was construed to require flexibility and planned management. It was observed that individuals who were flexible in their approach seemed to successfully adapt diabetes management to their social life, while those who were rigid in their management would cut down on social activities and find self-management difficult and limiting. Planned or strategic management helped individuals to use problem solving techniques to ease their way through management. On the other hand, individuals who found it difficult to self-manage reported using 'deliberate cheating' instead, which was their way of mismanaging diabetes in a 'calculated' fashion.

With regards to thought control, some participants had success stories to recount, and talked about controlling stress and developing the right mind-set about diabetes. These tended to accept their diabetes and reported not being highly affected by its management. On the other hand, other individuals had problems with thought management. Some reported becoming anxious about diabetes complications. Others saw diabetes as restrictive and as rendering them different to others. They tended to feel unlucky, resorted to self-pity and some of them found it difficult to accept their condition. Rejection of diabetes was projected through anger and denial, which sometimes lingered on for years after diagnosis. Overall, individuals who responded negatively to their diabetes seemed to 'struggle' to cope.

Part 2   Discussion of findings

6.5   Introduction

This section will discuss findings presented in the previous section, with reference to related literature, focusing on both behavioural and psychological management of diabetes.   Each section will address a particular element of the emic DSMS. Although the emergent strategy as an integrated whole is new to the literature, each of its elements (such as flexibility and positive thinking) has been well researched in terms of its influence on coping, utilising both qualitative and quantitative research methods. However, in some areas application to diabetes self-management is scarce. Also, no Maltese research in this area of self-management has been found, such that all the literature included is foreign.

Sections will examine how the literature defines each element and how this has been found to influence coping.   The focus will be on the potential benefits of each element.   The concluding section will then link all the elements of the emic DSMS and discuss the strategy as an integrated whole. The aim is to enhance understanding of the emergent strategy for self-management, and establish whether and how it should be supported. The main two sections of this discussion address behavioural and psychological management approaches separately.

6.6   Behavioural management

As mentioned earlier, although participants identified various behaviours which need to be adopted to manage diabetes, their contributions can be grouped into two general approaches towards achieving behavioural change, and which they felt facilitated this change.   These include 'flexibility' in management and 'planning ahead', the latter being related to proactive coping.   Studies have addressed both these approaches.   Flexibility has been studied almost exclusively in relation to diabetes, while proactive coping has been generally studied as a management strategy for coping with life threats and there is little work which applies this concept to diabetes management.

6.6.1   Flexibility

Participants talked about needing to be flexible in their management. They associated this with 'working around' or 'bending' the rules of self-management as necessary, particularly to be able to participate in social activities involving food. Individuals would strategically do something to retain a balance in blood glucose in the process. The emphasis placed on participating in social, often celebrative, occasions involving food has an important cultural relevance. In Maltese culture, social occasions and food are inseparable, and all get-together activities involve food. In fact, Maltese celebrate with food for various commemorations occurring throughout the year, such as religious occasions, village feasts, food and wine fairs…the list is endless. Flexibility was thus construed as a management approach which enabled them to enjoy and participate in these cultural activities, while retaining control of their blood glucose.

Flexibility as an approach to self-management, is addressed in the literature and is often considered as a successful way to cope with diabetes and to adapt to it. Research examining this concept has rarely been conducted in cultures which place such a high regard on the social element of food, as was the case in this study. This may explain why flexibility may have been used differently by participants of this present study and also why its benefits are hereby interpreted in a slightly different manner. In fact, a close look at my data revealed that this concept could be problematic and requires an elaborate definition if it is to be considered as a desired approach to self-management. As indicated earlier in this chapter, some participants went to extremes when 'bending' the rules, for example by indulging in food or alcohol during festive occasions and then requiring drastic measures to overcome the impact of this behaviour on blood glucose. Here, participants lost the notion of being 'moderate' in their behaviour, although they were still strategic in their attempt to maintain normal glucose levels. This points to a continuum of flexibility along which individuals behaved, and the end points of which may be problematic.

The literature makes no reference to this continuum of behavioural reaction, failing to specify what extent of flexibility is conducive to self-management or the level of flexibility being referred to when discussing related evidence. This is considered as

a limitation across studies. For the sake of clarity, I chose to consider desired flexible behaviour amongst my participants as solely pertaining to that which involved moderate behaviour. I termed extreme flexibility as 'deliberate cheating.' Both flexibility and deliberate cheating signify ways by which participants coped with the difficulties of maintaining behavioural control in the face of challenging life situations. However, the latter may not always successfully offset the negative repercussions on glycaemic control resulting from 'bending' rules of management. This section will cover two main issues related to flexibility; what it entails as an approach to self-management and its outcomes in terms of coping with illness.

Amongst their sample of women with Type 2 diabetes living in the UK, Rayman and Ellison (2004) noticed that flexibility involved learning from experience and experimenting, possibly making mistakes in the process and using feedback from blood glucose values to adjust management routines. As they experimented, their participants realised that they could apply rules flexibly rather than adhere rigidly to them. This allowed them to adjust their management to their own unique circumstances. Parallel to these findings are those obtained more recently by Wilkinson *et al.* (2014) in their meta-synthesis of qualitative studies conducted in USA, Australia and Europe. Studies included in their review also reported that participants experimented and used past experience to guide their day-to-day management. These authors, in fact, refer to flexibility as 'experiential learning' due to the central feature of learning from past experience.

Experimentation and learning from feedback was used by participants in this present study, the focus most often being that of enjoying preferred food during social events, or adapting medications to their work requirements. They gave various ideas of how to regulate blood glucose in the process, using feedback from blood glucose monitoring. They acknowledged the fact that certain occasional behaviours might slightly and temporarily elevate their glucose levels, but they accepted this and considered it part of their coping process. This is tied to the findings of Rayman and Ellison (2004) who discovered that their participants, on being flexible, became accepting of some fluctuation in their self-management, and of the fact that they did not have to be 100% successful every single day.

Campbell *et al.* (2003) carried out a meta-ethnography of seven qualitative studies which examined perceptions of diabetes. Studies included in the review were mostly conducted in Europe and America. These authors identified key concepts in enabling a person with diabetes to achieve balance in their lives and flexibility was found to be central to this process. Campbell *et al.* (2003) found that using flexibility in a strategic fashion, generally freed individuals from a sense of guilt, which is normally associated with non-adherence. Putting thought and reflection into how to overcome negative repercussions of 'bending' the rules, helped individuals feel that they were still in control. This was also reflected in the way participants of this present study talked about their flexible behaviour, referring to this with a sense of pride and achievement. Feelings of satisfaction from those who were flexible, came from realising how they could be practical in their self-management and assume control over their blood glucose, in line with their needs and preferences and sometimes in opposition to what was imposed by their doctors. This may be linked to observations made by Campbell *et al.* (2003, p. 680) in their meta-ethnography, whereby it was found that with applying flexibility, patients no longer remained "passive recipients of medical advice," but rather active interpreters and decision makers. It was noted in this present study that those participants who deliberately cheated in their management, despite knowing that their behaviour was not so advisable, still did not feel guilty about it. However, they were not generally open about their approach and were pleased to realise during focus groups, that their measures were common to others. This was reflected in the banter that took place in the group when this was discussed.

Flexible self-management has been associated with better coping. For example, in this study, I found that individuals who were flexible in their management were more likely to manage their diabetes 'with ease' as opposed to 'struggling' to self-manage. These participants were also more likely to report a positive psychological response to having diabetes. This was also revealed by Rayman and Ellison (2004) who reported how those participants in their study who used flexibility did not feel consumed by their diabetes, were satisfied with their management and reported acceptance as opposed to resentment as a result of having diabetes. With reference to findings of his Grounded Theory study amongst individuals with diabetes, Hernandez (1996) explain how flexibility enhances coping through facilitating

integration of illness with oneself. With regards to this concept, Bury (1982) and Hermandez (1996) refer to how, when individuals or health professionals objectify diabetes and consider it as separate from the self, they tend to focus on the medical management of the condition and forget about social needs of the individual. Flexibility tends to combine medical and social dimensions of care. By being flexible, participants use medical knowledge and apply it within the context of their social life, thus integrating the 'self with diabetes' with the 'social self.'

Researchers who have divided the process of coping into chronological stages have observed that flexibility was key to enabling individuals to progress from one stage to another (Kelleher, 1988; Hernandez., 1996; Rayman & Ellison, 2004). They discovered how individuals in the initial stage of coping would either be very rigid in their approach or have no sense of control whatsoever, while those in the advanced stage of coping would exhibit flexible management. To this extent flexibility has been viewed as being central to learning how to self-manage. This present study has given a slightly different and more complex interpretation to this phenomenon. This is due to the fact that while flexible behaviour was associated with high levels of coping (finding management 'easy'), deliberate cheating was common amongst those experiencing 'moderate' difficulty. Thus, according to my findings, different extents of flexibility, which feature moderate or not so moderate behaviour, are related to different levels of coping.

Despite the capacity of flexibility to facilitate coping, Paterson *et al.* (1999, p. 797), who studied the process of transformation of oneself after being diagnosed with diabetes, found one important drawback with using flexibility in the transformation process. Their participants, who, according to the authors were all exemplars of self-management, reported experiencing a tension between "feeling autonomous and liberated and feeling alone and solely responsible" when basing their management on flexibility. The burden of decision making related to how and when to work around rules and in the process keep blood glucose levels normal, falls entirely on the patient who may feel overwhelmed with the associated responsibility. In fact, Hermandez (1996) has stressed the need to support flexible behaviour to make related 'work' less burdensome. Individuals with diabetes need to be respected as responsible adults and during consultations their decisions related to flexibility need

to be discussed without judgement. This is because, according to Hermandez (1996), it is so easy for these to be considered as non-compliant patients. Furthermore, as I have found in this study, participants may go to great lengths to bend the rules, and use drastic measures to minimise the impact on their blood glucose. Thus, education, feedback and guidance from health professionals becomes crucial.

Many of the studies mentioned above which examined the concept of flexibility and its influence on coping, are quite old and this points to an important limitation. This is because recent trends in medications and dietary advice (such as carbohydrate counting) increasingly support flexibility. Attitudes of health professionals towards flexibility could also have been improved. In Chapter 8, an analysis is presented which determines whether or not flexibility was supported by health professionals who cared for participants of this study. Also, whilst a number of qualitative studies have consistently found that flexibility and coping coexist in diabetes self-management, this association has not been examined using quantitative measures. This points to an important gap in the literature, which at the outset, needs to define and quantify one's ability to be desirably flexible. Quantitative studies could also examine the impact of flexibility on biological outcomes, such as HbA1c, and identify attributes needed to apply flexibility in management, such as experience and cognitive abilities.

In this study, I have found flexibility to be linked to another strategy which participants found useful, that of 'planning ahead' or proactive coping, which is discussed in the next section. These approaches are linked because they both facilitate behavioural adaptation to diabetes, they both require problem-solving skills and to some extent, they both necessitate some form of proactive thinking. However, planning ahead, although sometimes used to facilitate flexibility, is not always associated with the 'bending' of rules. In fact, planning ahead was often used by participants to make adherence to these rules easier.

6.6.2   Proactive coping

Participants, particularly those who found self-management 'easy,' spoke of how they liked to plan ahead (or to act proactively) so as to reduce potential threats to behavioural control.   Such threats could include a sudden urge or temptation to indulge in restricted food during parties, or getting caught up without tablets, due to an unforeseen need to work late.   Planned strategies to avoid these threats would include going to parties with a full stomach or keeping extra tablets at the place of work.   Planning ahead was again mostly used to manage cultural threats related to food.   For example, an elderly participant who loved to give ice-creams to her grandchildren when they visited would prepare an iced yoghurt for herself so she could safely enjoy the dessert with her young relatives.   Both the giving of sweets to grandchildren and the frequent consumption of ice-cream in Malta's hot climate have cultural connotations.   This type of planning to avoid threat is associated with proactive coping, a strategy which has been well researched in relation to adaptation to life challenges in general, but less so in relation to diabetes.   With reference to this literature, mostly quantitative in nature, this section will address evidence which has highlighted the benefits of proactive coping and its connection with psychological and emotional well-being.

Proactive coping as a concept was first introduced by Aspinwall and Taylor (1997) who viewed such coping as the continual anticipation of factors which can act as barriers to achieving desired goals and the ability to plan and implement a strategy to offset these barriers.   In the process, individuals use personal and environmental resources.   For example, in this present study, participants who reported disclosing their diabetes with friends and colleagues would intentionally do this so that they would be able to help them out in the event of a hypoglycaemic episode (sometimes referred to as a 'hypo').   Thus, they *planned* how to utilise family and friends as *resource*s to help them manage a hypo.   Greenglass and Fiksenbaum (2009) write that proactive coping differs from traditional beliefs about coping in that it is not reactive (occurring after the problem arises), but rather it takes place before problems occur, involving not merely a response to negative events, but the actual creation of opportunities and positive experiences.   A related example from this present study is how a participant who used proactive coping made sure he always

had a supply of tablets at the workplace, while another male participant who had no such strategy in place, spoke of the exigencies resulting from forgetting to take his tablets to work. When caught without tablets, he would be unsure as to what and how much he should eat to compensate for the missing dose. The need to respond reactively to the negative event, confused and distressed him.

Studies have investigated the outcomes of proactive coping in different life situations and have shown that individuals who use such a coping strategy are more successful in avoiding threats or minimising their impact and are more likely to achieve successful outcomes and long-term goals (e.g. Vernon *et al.,* 2009; Tielemans *et al.*, 2014; Searle & Lee, 2015). With a focus on chronic illness management, Wilson *et al.* (2007) examined characteristics of individuals who were 'experts' in self-management, in order to explore the relationship between these characteristics and different forms of self-management education. The authors found that proactive coping was key to becoming a self-management 'expert.' The main proactive activity observed was information seeking, which enabled participants to discuss management issues with their professionals during consultations. This kind of proactive activity was uncommon amongst participants of this present study, who, as will be shown in Chapter 8, were very passive when it came to gaining information and were hesitant to discuss treatment options with health professionals. This behaviour was found to be related to certain cultural trends. This shows that individuals may indeed pick and choose the kind of proactive behaviour to use in everyday life and this choice is likely to be influenced by socio-cultural issues which determine priorities in self-management.

A study of proactive coping amongst individuals with diabetes was carried out by Thoolen *et al.* (2009) who examined the influence of this skill on diabetes outcomes. The authors tested their hypothesis that proactive coping is particularly helpful with achieving 'maintenance' of desired behavioural change. The authors point to the particular challenge imposed with maintaining behavioural change in the face of the many threats which life experiences present. They studied the effectiveness of a 12-week intervention programme which showed individuals with Type 2 diabetes how to be proactive in their management. The intervention was effective in improving psychological and behavioural outcomes over a twelve-month period. A close

association was found between self-efficacy and proactive coping, both of which improved with the intervention. The intervention used by Thoolen *et al.* (2009) was also examined some years later by Kroese *et al.* (2014) where individuals with diabetes were observed for a longer period of time (15 months). Participants were again observed to develop better proactive coping as well as self-efficacy after the programme and to demonstrate better self-care behaviours, these attributes remaining stable throughout the follow-up phase.

The above studies, which examined the influence of proactive coping on diabetes outcomes, have both found an association between proactive coping and self-efficacy, this association being also found by Vernon *et al.* (2009) who examined the relationship between proactive coping and other psychological characteristics amongst 182 women with a history of trauma. This indicates a potential connection between proactive coping and some form of positive thinking. This connection was highlighted by Zhou *et al.* (2013) and Greenglass and Fiksenbaum (2009) who stated that proactive coping requires individuals to acquire a positive perspective on perceived barriers, appraising these as challenges rather than threats. Perceiving barriers as non-threatening means that demands for behavioural change are not seen as exceeding one's coping resources (Greenglass & Fiksenbaum, 2009), this notion being highly related to self-efficacy. In fact, in this present study, individuals who coped proactively and who reported having to drastically change their lifestyle after diagnosis were not overwhelmed by the need for change, as did other participants who 'struggled' to self-manage. Rather, these participants would stage their goals in a realistic fashion and looked back with satisfaction at the way they responded to these life challenges.

In line with the arguments brought forward in the above section, Chew *et al.* (2014) point out that with proactive coping in diabetes self-care, individuals need to focus on the immense possibilities of distant future threats, as well as the demands of the present. This may be emotionally overwhelming and thus requires a high degree of support, as well as emotional and cognitive agility. It is thus expected that individuals who succeed with proactive coping would possess emotional resources. This has been supported by various observational studies (unrelated to diabetes care), which have found that individuals who carry out proactive coping also demonstrate

positive emotional, as well as psychological responses to life situations, including less stress and depression, and greater optimism (Uskul & Greenglass, 2005; Greenglass *et al.*, 2006; Vernon *et al.,* 2009). In line with this evidence, I found proactive copers to be more likely to report positive psychological responses, such as acceptance and optimism. This highlights the link between behavioural and psychological responses to diabetes.

Participants' definition of self-management extended beyond the need for behavioural control, which was discussed in this section, to include approaches towards thought management. Successes and failures of participants to achieve thought control have been highlighted in earlier sections of this chapter and will be discussed with reference to literature in the next sections.

6.7   Thought management

Participants commented about how, on being diagnosed with diabetes, they were confronted with the need to alter preferred ways of living and assume different personal identities to those held before knowing about their chronic illness. This presented challenges which required psychological adjustments. Thus, participants talked about needing to control stress, be positive, and accept their diabetes, as a means of coping with its demands. This was a unique integrative way of viewing psychological management of diabetes, despite the fact that individual elements of this comprehensive approach have been addressed in the literature. This section will discuss how aspects of this strategy have been investigated in terms of chronic illness management.

6.7.1   Stress management

Participants referred to stress as a significant hindrance to self-management. They viewed the need to control stress related to everyday life, but most especially that which is triggered by having diabetes.

The most common source of diabetes-related stress was fear of long-term complications. This finding has been reported in other studies exploring diabetes-

related views and experiences across different cultures, to include American studies (Wood & Jacobson, 2005) as well as English (Turner, 2008), Australian (Furler *et al.*, 2008) and Chinese studies (Shiu & Wong, 2002). Fear associated with the disabling outcomes of diabetes complications seems to have no cultural boundaries and may haunt the minds of those who have difficulty controlling related anxieties. In fact, participants reported being apprehensive about their future because of this issue. Drawing upon her work with chronicity, Charmaz (2011) states that continued uncertainty about the future is the reality for many of those who live with chronic illness.

In this present study, the psychological struggle related to fear of complications, seemed to be the only one affecting practically all participants to some extent, regardless of their other successes with coping. Repeatedly, participants mentioned feeling scared when reflecting upon their relatives' or friends' experiences of complications, such as amputations or blindness. This was a constant reminder of their most dreaded threat. At this point, one should mention the high prevalence of diabetes in Malta and the fact that family lives and feels close because of the geographical size of the island and the prevalent culture of extended families. This caused individuals to closely experience the suffering related to diabetes complications amongst others they knew. Their knowledge about complications extended far beyond what they read or what they were told by health professionals. This highlights cultural influences on thoughts related to diabetes which are likely to induce stress in a unique way. I was not able to establish whether this stress-related problem is worse in countries such as Malta, since quantitative studies about the fear of long-term complications could not be traced, even though instruments to measure this attribute have been devised (Taylor *et al., 2005)*.

Besides fear of complications, stress was related to a number of other negative psychological responses, such as feeling restricted, feeling like a failure, feeling obsessed with management and feeling guilty of mismanagement. Stress induced by these psychological responses, is related to what has been termed as 'diabetes distress' (Sturt *et al., 2015)*. This phenomenon reflects a range of different emotional responses to the challenges of living with diabetes (Snoek *et al.*, 2015), such as that associated with food restriction. Elevated diabetes distress is not

uncommon and its prevalence has been found to range from 20 – 30% of studied populations (Sturt *et al.*, 2015). These authors also found diabetes distress to be linked to behavioural problems, such as low levels of blood glucose testing and poorer diet. In this present study. it was observed that those who felt stressed because of diabetes would report finding it difficult to manage their condition and their general outlook on life with diabetes was poor. In fact, experiences of diabetes-related stress have generally taught participants that preventing stress through managing thoughts about diabetes was the way forward to diabetes self-management. This would involve, amongst others, positive thinking which is discussed next.

6.7.2   Positive thinking

There was perhaps no other self-management issue where the participants' experiences varied so greatly as with positive thinking. For some, this approach was the way forward towards integrating diabetes in their lives and they demonstrated a number of ways in which they tried to create positive thoughts about their situation. For others, this was not even an option. They insisted that there was nothing positive about having diabetes. This psychological response seemed to make or break individuals' adaptation to this chronic illness, as it seemed to influence other forms of psychological and emotional coping.

Various studies have examined how positive thinking in general, influences coping with difficult life situations. Related literature uses the terms 'positive thinking' and 'optimism' interchangeably, as will be the case in this section. Studies examining optimism within the illness experience found this to be associated with a better adaptation to one's condition. For example, Carver *et al.* (2003) found that amongst women undergoing treatment for breast cancer, optimism protected them against the urge to withdraw from social activities and Brenner *et al.* (1994) found optimism to be associated with better psychosocial adjustment amongst individuals with rheumatoid arthritis.

While some individuals in this study had to make an effort to think positively about their diabetes, for others this almost came naturally from being satisfied with the way

they managed and content with their 'new self' which had emerged from experiencing diabetes. Some compared their current healthy lifestyle and weight with their lifestyle and the extra kilos they carried, before being diagnosed with diabetes. They were happy with the change, attributing their success to diabetes. They felt that this condition actually made them healthier people. Similarly, Broom and Whittaker (2004) explain how some of their participants felt diabetes enabled them to correct their past wrong doings, their accounts being weaved within stories of redemption. Hornsten *et al*. (2005) report how individuals in their study viewed diabetes as giving them the mental strength they required to change their lifestyle, something they had failed to do in the past. With reference to studies on various medical conditions, such as cancer, rheumatoid arthritis, AIDS and fibromyalgia, de Ridder *et al*.(2008) explain how the experience of illness has been attributed to positive outcomes, such as an improved appreciation of life, better personal relationships and sense of purpose. The authors set out to examine the impact of this 'benefit-finding' attitude on other psychological responses to diabetes. They conducted a study involving 121 adult patients with diabetes and found that those who perceived a benefit from having diabetes also demonstrated a better psychological adjustment to their condition than those reporting losses and they had less depressive symptoms. Sharpe and Curran (2006) refer to other research, such as that carried out with patients having lupus or cancer, which has associated benefit-finding to less distress and symptomatology. In view of this evidence, de Ridder *et al.* (2008) explain how individuals' effort to find benefit from illness could be an effective cognitive strategy used to offset its negative repercussions.

The phenomenon of benefit-finding has been associated with the so-called 'response shift process' described by Sprangers and Schwartz (2000). These authors explain how individuals change their internal standards and values related to aspects of quality of life when faced with situations, such as chronic illness. That is, they change their expectations or beliefs of what is important, given their new circumstances. This enables them to view life changes which they undergo as beneficial in the light of their newly established standards. In the process, they maintain an acceptable quality of life, despite their new limitations. The best example of this process from this present study is the case of a single male participant in his late twenties, whose life before diabetes revolved around having

late nights out with friends, bingeing on alcohol. This is what he lived for. After his diagnosis, he reduced this activity, saved up money and bought a small business which he could only sustain with his new lifestyle. By the time of his interview, his business had become the focus of his life. He considered this as his biggest achievement and attributed it all to his diagnosis. By then, his values were focused on his financial stability and his previous bingeing no longer had meaning in his life.

Though other participants were exemplars of benefit-finding in other ways, it was clear that certain values which were culturally embedded, even though directly influenced by diabetes, could at times not be scaled down in priority. A case in point is festive celebrations involving food, so popular with many Maltese people (Baldacchino, 2011). Celebrating these cultural activities remained important and opting out signified becoming an outcast. Individuals thus went to great lengths to retain this as a valued activity, despite their diabetes. In the process, they tried to minimise its repercussions on their blood sugar levels, as was feasible within their coping abilities, such as through using flexibility or deliberate cheating. Adding to our understanding of the response shift process, this finding shows how individuals are involved in scrutinising options when revising their internal standards, tending to preserve their cultural values in the process.

For participants, positive thinking extended beyond benefit-finding and included other mental strategies which helped them focus on the brighter side of their experience. These included comparing their situation with worst case scenarios, or focusing on the positive rather than the negative information about their health, as given during follow-up visits. With reference to different forms of positive thinking, Fournier *et al.*(2002, p. 410) report how in chronic illness, outcomes of positive thinking may be determined by the type of optimism engaged in and the self-care requirements of the illness involved. For example, the authors refer to "positive efficacy expectations" as one type of optimism characterised by one's confidence in his/her ability to handle a situation, this being a key component in social cognitive theory (Bandura, 1988). This was considered by Fournier *et al.* (2002) to be particularly helpful in coping with chronic illness requiring complex self-care behaviour as part of management.

Another type of optimism, namely "positive unrealistic thinking" (Fournier *et al.,* 2002, p. 410) is a strategy used by individuals who mentally distort reality by accentuating positive aspects of their health and playing down problematic ones. This may involve dissociating oneself from negative information when developing expectations about one's illness. In their review of adaptive strategies to chronic illness, Telford *et al.* (2006) refer to a number of studies which have found positive unrealistic thinking to be a helpful coping resource in threatening situations and to be congruent with mental health. However, Weinstein (1980) writes how this form of optimism, despite preventing anxiety may at the same time, distort beliefs of vulnerability. In so doing, it may hinder one's motivation to carry out health behaviours (Weinstein, 1980). More recent work in this subject area has concentrated on the impact of unrealistic thinking on preventive behaviours, such as screening. Results have been inconclusive. Some studies, such as that carried out by Gu *et al*. (2012) failed to find any correlation between unrealistic optimism and uptake of screening while other studies, such as the one conducted by ten Hoor *et al.* (2013) demonstrated a negative correlation between the two variables.

Fournier *et al.* (2002) studied patients with different chronic illnesses to examine the outcome of various forms of positive thinking on chronic disease management. The authors found that positive efficacy expectations were related to less anxiety and better physical function amongst individuals with diabetes, while amongst the same cohort, positive unrealistic thinking was not associated with either mental or physical health. These findings support Weinsten's (1980) arguments concerning the shortcomings of positive unrealistic thinking, particularly in conditions high in self-care requirements. No other research in this area could be traced, indicating the need of more studies about the role of different forms of positive thinking on diabetes self-management. While participants of this present study perceived the importance of positive thinking in self-management, most of them reported using positive unrealistic thinking, such as focusing on the good news given during consultations, rather than on less positive results. Positive efficacy expectations were rarely expressed, pointing to a possibly generally low level of self-efficacy beliefs. This was not explored further and could not be substantiated by other local research, but it could be related to evidence which proposes that these efficacy beliefs can be culturally determined, as will be explained below.

Klassen (2004) carried out a review of studies investigating differences in self-efficacy beliefs across cultural groups, analysing a total of 20 cross-cultural studies. He found that levels of efficacy beliefs were consistently lower in collectivist (non-western) settings and higher in individualistic (western) settings. There are various cultural characteristics which differentiate collectivist from individualistic communities and these will be explored in relation to the Maltese community in Chapter 9. Perhaps the main deterministic trait, as pointed out by Hofstede (2010) is whether the community places priority on group interests, as opposed to the interest of the individual. The former is characteristic of collectivist cultures, while the latter is typical of individualistic communities. Klassen's (2004, p. 208) general argument is that the theory of self-efficacy, which states that beliefs in personal ability are key to human agency, is "firmly seated in a western, independent, individualistic context."

Collectivist influences on self-management amongst participants in this study have already been referred to in the previous chapter, when noting that Maltese culture could foster dependence on others in caring for one's own health, interdependence being one of the predominant features of collectivism. This same dependence may hinder self-efficacy beliefs. In fact, an association between these two characteristics has been identified amongst Maltese individuals with diabetes elsewhere. In an earlier study which I conducted on diabetes self-management amongst Maltese individuals, I found a high level of dependence on others for self-administration of insulin and this was correlated with low levels of confidence in one's ability to self-inject (Buttigieg, 2003).

Overall, evidence presented in this section has highlighted the positive impact of optimism on coping. Notwithstanding this, it has also pointed to the need to discuss these mental strategies with patients. While supporting their efforts to be positive, one may need to help patients focus this positivity on their ability to self-manage, albeit the challenge which may be imposed by cultures which foster dependency. Participants viewed positive thinking as helping them achieve another positive response to diabetes, namely acceptance. This mental strategy will be discussed in the following section.

6.7.3   Acceptance

Participants viewed 'acceptance' as the ultimate psychological strategy which would help them 'get used to their diabetes'. According to participants, once they accepted their condition, they did not remain highly affected by it. Participants referred to acceptance as a process whereby the individual ceases to mentally struggle against the idea of having the condition and give in to it. Participants viewed positive thinking as helping them gain acceptance. Those who failed to accept their diabetes reported feeling angry about their situation, or denying their condition. Their accounts featured strong negativity about the restrictive nature of self-management which is what instigated their anger and some would use denial to protect themselves against these feelings.

The use of acceptance and denial in coping with a traumatic event has long been the subject of study in research. While working with people having terminal illness, Kubler-Ross (1969) developed a model of grief whereby individuals are thought to move through stages of emotional adjustment. Denial and anger feature in the early stages and these are gradually replaced by acceptance in the final stage of adjustment, this stage being characterised by peace and resignation. Kubler-Ross (1987) extended her theory to other situations requiring coping. Although extensively quoted and used to guide practice, Kubler-Ross's work has been criticised in view of grieving being considered as a very personal experience which cannot be explained in a set pattern of emotional responses (e.g. Konigsberg, 2011). Notwithstanding this, and in line with views of participants in this study, the literature has identified positive outcomes from achieving acceptance (Kubler-Ross's last stage of coping) when living with chronic illness. A few of these studies have focused on coping with diabetes and these are presented next, following an introduction to the concept of acceptance.

Kresser (2014) writes that acceptance of chronic illness refers to the acknowledgement of the 'truth' about one's situation, or as seeing reality as it is and being at peace with it, rather than mentally struggling against it. This is very much in line with the way participants in this present study viewed acceptance as they spoke of their need to acknowledge and 'surrender' to the thought that diabetes was

now part of their life, and always will be. Participants' choice of words point to their initial psychological 'battle' against acceptance of their condition, characterising acceptance as a process requiring time. Schmitt *et al.* (2014) view acceptance of diabetes as integrating the physical, mental and social burden of the condition. This means that acceptance does not simply involve accepting physical symptoms, but also their impact on one's life and the feelings and sensations that go with this, such as feelings of loss or fear of the future. Kresser (2014) notes that avoiding these feelings will not necessarily make them go away. Rather, such avoidance may keep the individual back from taking action. In fact, acceptance has been dissociated with giving up or submitting to one's condition and Schmitt *et al.* (2014) write how this psychological strategy increases involvement in diabetes treatment and its integration in everyday life. This has been shown in quantitative studies, referred to next, which examined the impact of acceptance on diabetes self-management.

Richardson *et al.* (2001) and more recently, Schmitt *et al.* (2014) carried out studies involving 150 and 320 individuals with diabetes respectively and found acceptance to be correlated with better psychological coping, more achievement in self-care, better metabolic control and a higher level of health-related quality of life. Since both these studies were cross-sectional, one cannot conclude on the causal direction, and hence the possibility that acceptance actually *followed* the achievement of other positive outcomes, may hold true. On the other hand, the beneficial effects of acceptance as a coping strategy have been demonstrated by a small-scale controlled trial carried out by Gregg *et al.* (2007) amongst 81 participants with Type 2 diabetes. These tested the effectiveness of an education programme which included training on how to accept and be mindful of problematic diabetes-related thoughts and feelings. After three months, those undergoing the acceptance therapy reported better acceptance, better self-care and had lower HbA1c levels than the control group. Further to these studies, Besen and Esen (2012), while examining acceptance amongst Turkish individuals with diabetes, found this to be associated with life orientation, this being a measure of positive outlooks on life. This is in line with observations made in this present study, in that participants who were positive about having diabetes were noted to be more accepting of it.

That acceptance is conducive to coping with diabetes was a known fact to participants in this present study, but not everyone had yet reached this stage of coping. Some individuals talked emphatically about their anger and denial towards having diabetes, amidst feelings of frustration resulting from their perceived failure to adjust psychologically to their condition. Some had problems understanding how they could still be in denial years after their diagnosis. They acknowledged their denial as a coping mechanism but were aware that their distortion of reality was not helpful towards their behavioural management.

In particular, it was noted that participants *expected* to reach the stage of acceptance and got frustrated when they failed to do so. Besides realising that denial was holding them back from looking after their diabetes, they felt they were not abiding with the 'norms' of coping. For some, this seemed to reinforce feelings of failure, possibly dismantling their already fragile sense of self. Telford *et al.*(2006) write how this could result if denial is reinforced as a failed coping strategy by carers who may hastily categorise their patients into Kubler-Ross's (1987) stages of coping, and in the process, label them as successful or unsuccessful copers. There could also be a cultural explanation to participants' sense of frustration. In line with predominant Catholic beliefs in Malta, while illness is considered to be part of the human experience and not punishment from God, Catholics are encouraged to accept their illness and join their pain and suffering with that of Jesus Christ (Winslow, 2013). It may thus seem unacceptable to reject one's illness because of the suffering entailed.

If rejection is perceived as socially undesirable, it is less likely that related feelings are expressed and discussed with health professionals, family or friends, rendering acceptance of these feelings possibly more difficult to achieve. Another point worth noting is how denial was used by participants who lacked confidence in their ability to change behaviour. For these individuals, denial meant that they did not need to take action in relation to which they felt incompetent. Discouraging denial as a coping strategy involves replacing this with another strategy which neutralises the original need for denial. This may thus involve enhancing self-efficacy to help individuals disengage from using denial to cope with feelings of incompetence.

6.8   Conclusion

This chapter has examined the emic DSMS involving thought and behavioural management aimed at controlling diabetes and adapting to it. Each element of the strategy was found to enable coping among participants of this study, such that individuals who managed these elements well (such as through being flexible), were more likely to find diabetes management 'easy.' Remarkably, as discussed in the latter part of this chapter, in other research work each element of the strategy was also found to enable coping. This shows how during the interviews, participants reflected on their own experience, focusing on what does and does not work in their lives with diabetes.

An important finding was that elements of the emic DSMS were closely connected. For example, participants who were found to adopt positive thinking would also manage their diabetes in a flexible manner and were more likely to be proactive, while those who engaged in positive thinking would be more likely to accept their condition. Once again, these connections were supported by findings of other studies. Since practically all research work conducted in this area was cross-sectional, nothing can be concluded about the direction of the relationships. It is not clear whether helpful behavioural strategies (such as flexibility and planned management) bring about positive psychological responses (such as positive thinking and acceptance) or *vice versa*. However, the connections between the elements seemed so strong that these are likely to enhance coping through the links which hold them together. In other words, it could be that failure in one element of the strategy may cause the whole strategy to collapse.

Arguments put forward above, are supported by the way in which participants strived to manage all elements of the strategy, in an effort to keep the whole process of coping intact. When a specific element was perceived as particularly challenging, individuals would implement it using measures which were in line with their ability. For example, they would apply deliberate cheating to maintain flexibility or unrealistic positive thinking to retain a positive mind-set towards their health. They did this even though these strategies were not necessarily very appropriate. Possibly, their aim was to retain the principle of flexibility and positive thinking in their

strategy, such that it would not fail. This bargaining behaviour was mostly seen amongst those who were midway in the coping continuum, reporting diabetes as 'moderately' difficult. Unlike those who 'struggled' to self-manage, these participants managed to keep the strategy intact, but in ways which were not 100% in line with their idealised self-management. The message conveyed is that supporting self-management involves helping patients with each element of the strategy.

While discussing elements of the emic DSMS, ways in which these may be influenced by the socio-cultural context were revealed. For example, certain types of positive thinking were found to be influenced by cultural characteristics typical of collectivist societies. Furthermore, stress due to fear of complications seemed to be linked to geographical characteristics of Malta, and to prevailing norms related to family. Lastly, the high regard given to flexibility and proactive coping could be related to the fact that these helped participants overcome cultural challenges related to food. This was the beginning of the process by which cultural influences on self-management will unfold in this study. The following chapters will enable further understanding of this phenomenon by addressing factors which participants themselves perceived as facilitating or hindering their management.

Chapter 7

CATEGORY 3:
BEING IN A HELPFUL ENVIRONMENT

Part 1: Findings

7.1   Introduction

After presenting and discussing findings about how participants thought and acted towards diabetes self-management, the following two chapters will highlight factors which were seen to influence these thoughts and actions. This chapter will specifically focus on the perceived influence of the social environment on diabetes self-management.

Participants felt that to manage their diabetes they needed to adapt the way they thought and behaved. Thus they saw diabetes self-management as a way of life, and recognised that life is not lived in a vacuum. It is affected and sustained by that which goes on around it. To this extent, diabetes self-management was seen as being influenced by the environment in which it takes place. Environmental factors were described as hindering or facilitating one's ability to take care of his/her diabetes. In this chapter, three such factors will be addressed and treated as subcategories of the category 'Being in a helpful environment'. These include society's views about diabetes, the influence of family and the role of food culture.   The first part of this chapter will present findings related to the first two of these subcategories, and these are discussed in Part 2. The subcategory 'The role of food culture' was developed from findings which are presented in different parts of this thesis. This is because the influence of food culture featured in various participant accounts about self-management.   These findings will not be repeated in Part 1 of this chapter. However, when discussing this subcategory in Part 2, cross-reference will be made

to where related findings had been addressed. Figure 7.1 represents the main components of the category being addressed in this chapter.
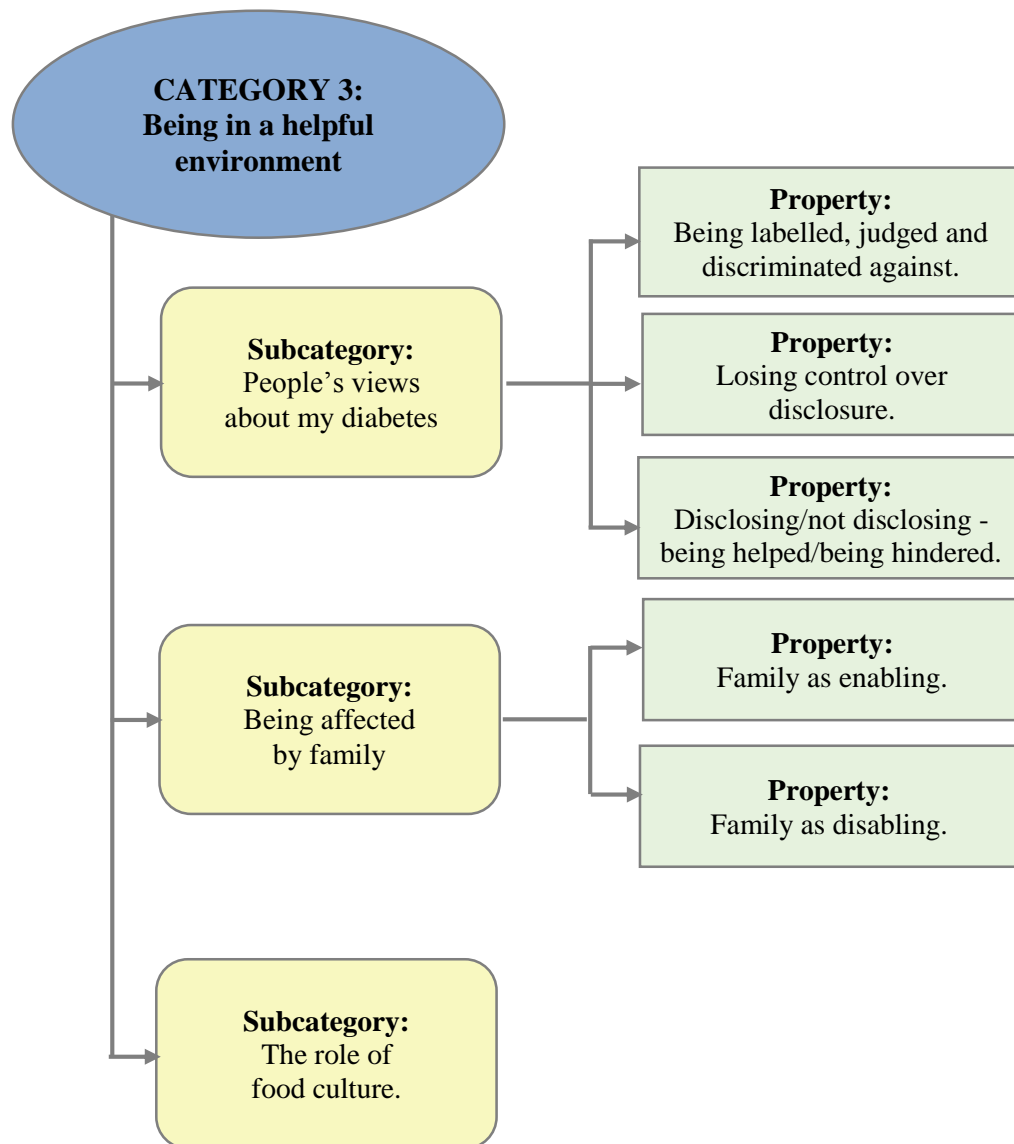
Figure 7.1 Elements of Category 3 including related subcategories and properties

7.2   Subcategory: People's views about my diabetes

This subcategory describes how individuals with diabetes may be affected by what others think about their condition. Findings suggest that the way in which the Maltese population generally regards diabetes influenced how participants viewed themselves in relation to others. Consequently, this affected their behaviour towards their condition, when in the presence of others.

It was noted that participants held opposing views about how diabetes is perceived in the eye of the public. Some felt that their community held negative perspectives about diabetes, which were seen to be more disapproving and stigmatising than those related to other chronic illnesses. As a result, these individuals hesitated to disclose their diabetes to others. Other participants disagreed that diabetes carries a stigma. They were comfortably open to disclosure as they felt that their condition did not render them different or inferior to others.

Individuals who felt stigmatised were in the minority, but this fact has to be interpreted with caution and will be discussed later on in this chapter. Most of this section will focus on the unique experiences of these participants. It will address issues surrounding their disclosing behaviour, such as why they chose not to disclose and the extent of control they assumed over disclosure. These issues will represent properties of this subcategory. The last property addresses outcomes of disclosing behaviour.

7.2.1 Property: Being labelled, judged or discriminated against

This property is about *why* some individuals felt uncomfortable disclosing their diabetes to others. Individuals who avoided disclosure expressed concern about being labelled as 'devalued' individuals, about having their behaviours judged by others, or about being discriminated against because of their diabetes. This is explained in this section.

Participants who felt stigmatised construed that in the public eye, a person with diabetes is fraught with limitations. They felt that this rendered the individual different from others in terms of his/her health and behaviour. A female participant spoke of how a person with diabetes is considered to be one who cannot live a normal life, due to the various restrictions he or she faces. A male participant thought that individuals with diabetes were considered unhealthy. The exact word used "*marradi*," specifically means a person who is liable to frequent and multiple illnesses, denoting considerable physical limitations. Although age is not supposed to impinge on the value attributed to a person, participants also considered diabetes

to be stigmatising because it is associated with older, frailer individuals. In relation to these issues, having diabetes was associated with a lowered self-value.

> [on disclosing my condition] I lower my image. Before telling them that I am diabetic, they would have had a good image of me, that I am still fit even though I am 58, for example. [They would think that] I am still a smart person, sort of. Once I tell them that I have diabetes, then they lower my score ... that is how I see it. (Adrian, 50Int)

Metaphorically, this participant continued to explain how, on disclosing his condition, he is no longer considered to be a racing horse of a first class category. He becomes a second class citizen. Adrian even spoke of how diabetes, being associated with physical weakness, also challenged his image of masculinity.

> The thing is that it bothers you to tell certain individuals that you have diabetes, or rather for example, when you are in the company of some female friends, in order to project yourself as a *hero* or *cowboy*, you don't tell them that you have a condition, diabetes. (Adrian, 50Int)

These thoughts about being devalued reflect the feeling that having diabetes is an embarrassment, which is why individuals who held these beliefs felt uncomfortable disclosing their condition to others. Participants were not just concerned about what others thought of them, but seemed preoccupied by how these 'others,' would then react towards them. For example, some felt likely to be pitied by those around them. They resented this reaction as it consolidated the imposed sense of inferiority.

> I hate to be pitied, I do not want them to pity me because I have diabetes, because, even for example [they would say] "What a pity, how young you were [when you got diabetes]" There is no need [to be pitied]. (Sandra, 18Int)

On the other hand, others felt susceptible to being bullied by those who were inclined to take advantage of their shortcomings. For a female participant, being devalued by a health issue, meant being more prone to social insult. She thought diabetes made it easier for those who are 'not so well meaning' to embarrass her

when the opportunity arose. Her reference to a particular incident explained how, with this kind of thought process, she interpreted the behaviour of others, as spiteful.

> .....then they maliciously remark about you. I was at the green grocer's and there were a couple of these individuals and one of them said, " [I want some of] that, that and that, because I can eat anything as I do not have diabetes." I felt like....I did not say anything. I felt that she was referring to me. (Judith, 50FG)

Being judged was another reason why individuals felt uncomfortable disclosing their diabetes. As mentioned in Chapter 5, participants associated having diabetes with responsible action towards achieving behavioural control and felt that they were *expected* to achieve such control. Consequently, some feared being judged if they failed to do so. A female participant was reluctant to disclose to individuals who could observe her behaviour and make judgements about it. Speaking about occasions when someone at work gets a birthday cake, she stated the following:

> ....if you say you have diabetes, then if you take a piece of cake, you sort of feel that others may say "she is eating sweets, despite her diabetes." So I want to feel free. I know when I should keep back and if I take a piece, I would know its effect on my diet ... and you would not want to be judged. (Anne, 50Int)

Another participant, Sandra, had concerns about judgemental issues of a slightly different nature. She felt that she was being judged by others for bringing diabetes upon herself, as shown in the excerpt below. Sandra was open to disclosure, but referred to this issue as rendering her disclosure problematic.

> Many individuals, for example because they see I am overweight, [...] [they say] that I brought [diabetes] upon myself. For example, my mother is very supportive, but there would be instances when she would say "Serves you right, you knew exactly what you were doing." There will be times when she would say this. (Sandra, 18Int)

A male participant also put forward the issue of discrimination and diabetes, particularly in relation to employability. He felt that acknowledging one's diabetes to employers or potential employers would decrease one's likelihood of being retained in employment or being employed in the first place. Consequently, he

conveyed a sense of apprehension about letting his employers know about his condition.

> Unfortunately, in Malta, and it's not just with diabetes, but with any other condition, immediately [the employer would say] "He has a problem, so we need to be careful, because [...] we are not going to get 100% work [from him]." Therefore, you become afraid to talk about your diabetes with your colleagues or with your boss. (Daniel, 40FG)

This belief seemed to have its own repercussions. For example, Daniel felt that asking for a minor concession, such as a permission to have a two-hourly snack because of his diabetes might result in him being labelled and losing his job. Another participant also feared losing his job if he took more sick leave than his fellow employees.

> …if due to your condition you avail yourself of a lot of sick leave, then I think you have a bigger chance of being labelled. (Stephen, 30Int)

7.2.2 Property: Losing control over disclosure

While individuals talked about choosing to whom they disclose, this element of choice was not always up to their discretion. Certain situations made it impossible for individuals to keep their diabetes a secret. This seemed to elicit feelings of frustration, as well as anger towards the systems or situations that imposed disclosure.

Malta is a tiny island and being one of the most densely populated countries in the world, its inhabitants tend to encounter each other at any place including the hospital, clinics and at social gatherings. Consequently, it is extremely likely that when, for example, you attend a follow-up visit at hospital, you would come across individuals you know. This, in itself, makes it difficult to keep your diabetes confidential. A male individual spoke of how, when attending a diabetes education meeting, he had to reluctantly disclose his condition to a friend, causing problems in their relationship.

I do not think you can hide your diabetes because once I was invited to a meeting […] organised by the Diabetes Association and I came across a friend of mine there. He said, "So are you diabetic?" I said, "Yes", he said, "You never told us." But why do I need to say these things? (Alex, 60FG)

While incidents such as the above are frustrating as they impose an inability to control personal information, the geographical constraints which cause the problem cannot be changed. Individuals, however, felt bitter anguish at situations where disclosure was enforced by the behaviour of others. A female participant projected these feelings as she explained what happens when she gets her drugs from the local pharmacy. Her feelings seemed significantly intense as she mentioned this issue twice during a focus group and on one occasion she actually stood up and role played the incident.

I feel these [health issues] are confidential. The pharmacist would say "You have these [tablets] for diabetes, these for cholesterol, these for hypertension, you have these [pills] for this and this ..." [At the pharmacy] there would be a couple of individuals whom you know [and they hear what is being said]. (Judith, 50FG)

A younger male participant also showed reservations towards a system used in hospital whereby documents issued from a department (such as the Diabetes Outpatients Department) would be stamped, indicating from where the document was issued. This meant that if this participant needed a letter certifying his attendance at the clinic, this would automatically divulge his condition to whoever processed this letter.

Even the fact that they give you a document … that really annoys me … when you come here [at the outpatients department] and you need a certificate for the workplace, they stamp it 'Diabetes Clinic.'[...] [this would be] a letter which shows that you have attended a hospital clinic [during work time]. In fact, until now, I have never needed such a letter, [….] but if ever they had to ask me for it and make me get it, I will ask the nurse at the reception not to stamp it for me. (Stephen, 30Int)

7.2.3 Property: Disclosing/not disclosing - being helped/being hindered

This property is about the consequences of disclosing one's diabetes. Participants' accounts showed how disclosure supports self-management, as opposed to hiding diabetes from others. This is explained in the sections below. The first part addresses how medication taking was affected by avoiding disclosure. The second part compares various other experiences between those who disclosed their diabetes and those who did not.

Taking medication is often associated with disease management and hence, with ill health. With most chronic illnesses, tablets are taken regularly. Hence, as conveyed by participants, letting their workmates watch them take their tablets every day, made it difficult for them to hide their diabetes.

> Because normally [medication taking] would happen more than once, if it happens at specific times or this sort of thing, you would not like others see you take tablets. (Adrian, 50Int)

Participants used strategies to take their medications 'in secret.' One male participant chose to be watchful of his work mates when it was time for medication, and swallowed them when others were not looking. Another participant took his tablets in the bathroom while a couple of participants chose not to take their medications at work. As one of them pointed out, this often meant prolonging or shortening the time interval for medication taking according to working hours. Not adhering to a desirable time schedule for medications, diminishes their therapeutic value. In fact, this participant's blood glucose was not well controlled and he attributed this to the way he was taking his medications.

Participants who avoided disclosure expressed other difficulties encountered in relation to this behaviour. This did not apply to those who were open to disclosure. For example, those who avoided disclosure said they would have problems with attending education classes if these were held in the community, as this would make their diabetes known to other community members. Unlike others who were open about their condition, they were reluctant to ask for desserts which were suitable for

their diet when eating at a restaurant and when at a party they had to think of 'excuses' for not eating sweets. A young male participant spoke at length about how being open to disclosure helped him manage his condition better. Family, friends and neighbours who had been informed of his condition were then in a position to support him when necessary.

> Even with barbeques or this sort of thing, like we would be eating at my friends'. [...] We would eat rabbit, for example. They would fry theirs, but they would prepare mine as stew. They have become used to me. (Frankie, 18Int)

Issues surrounding stigma and disclosing behaviour are presented in Figure 7.2. This figure and others that follow, will illustrate how I grouped my findings according to the coding paradigm which Strauss and Corbin (1998) developed so as to act as a framework for data analysis. With grouping data into **conditions, actions** and **consequences** (as illustrated in the paradigm), I could better explore the interactions that happened between the social context and the individual with diabetes. This paradigm was introduced and explained in Section 4.5.5.2.
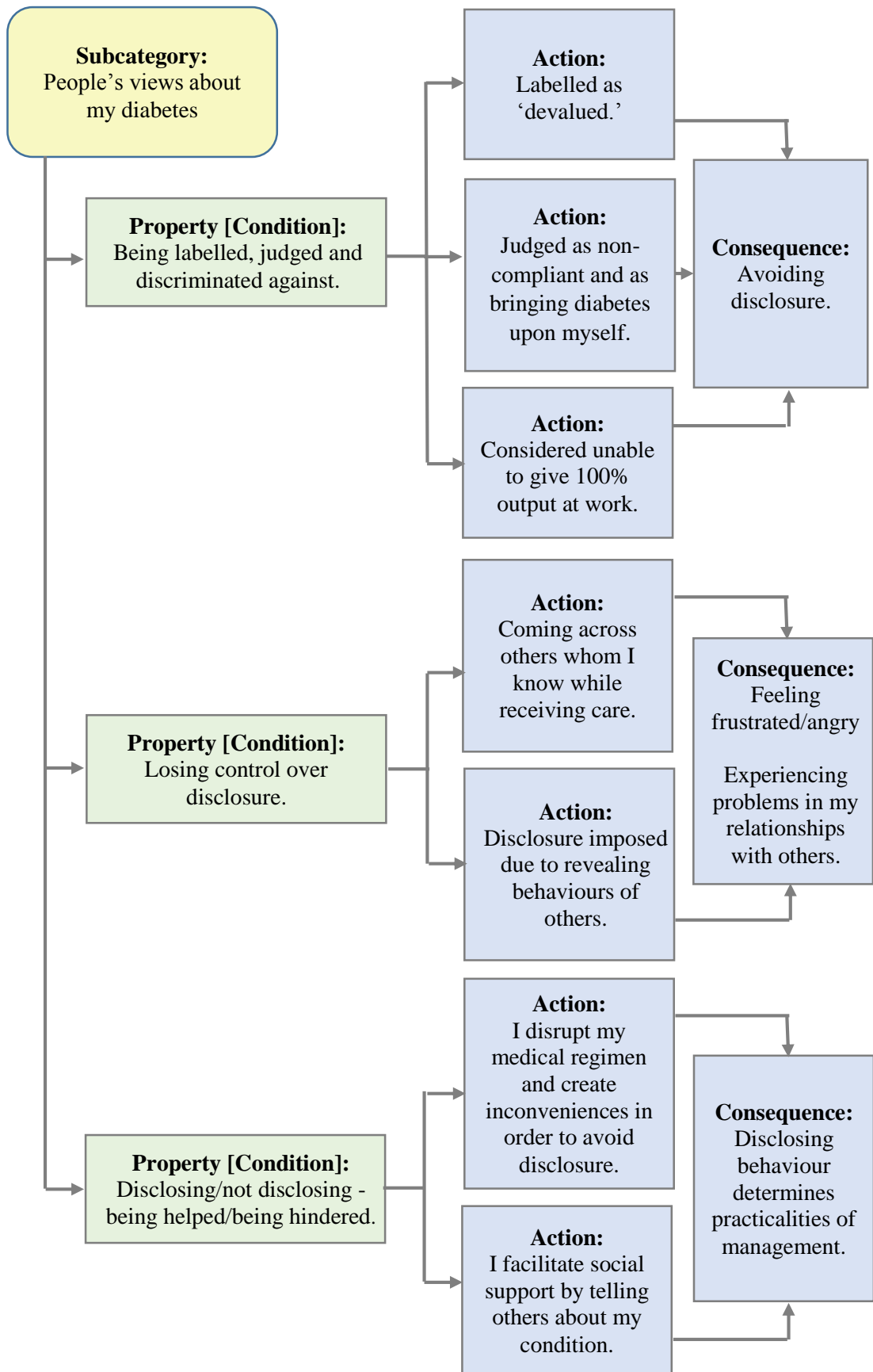
Figure 7.2   Issues surrounding stigma and disclosing behaviour

7.3 Subcategory: Being affected by family

The role of family in diabetes self-management was the subject area which was most commonly brought up by participants. Family featured in all interviews and was discussed by all, irrespective of age, gender and marital status. Family issues weaved themselves finely into the lives of all and were seen to affect diabetes management in a complex manner. Family could sometimes be supportive, yet at others it could act as a barrier to effective management. And family affected males and females differently. This was unique in that it was the only factor in which a significant difference was noted between genders. The two properties in this subcategory will address how family helped or hindered individuals in managing their diabetes. The words 'partner,' and 'husband' or 'wife' are used interchangeably, but will always refer to a person of the opposite sex. Participants who were in a relationship referred to their partners as being so.

7.3.1 Property: Family as enabling

Participants talked about the importance of family support in managing one's diabetes. In general, family was considered as supportive when it made it easier to adhere to diabetes recommendations, such as when someone prepared the right food or reminded the person of his/her medication. But support was not just about practical help. It was also construed to be about knowing there is someone who cares about your diabetes and takes an interest in it. This was about feeling generally or emotionally supported.

Younger participants received support from their parents and older adults generally got support from their partners. However, males were more likely to report receiving support than females. Also, the type of support received from female and male partners was different. Support from females, besides being practical, such as with cooking the right meals, was also likely to be of an 'emotional' type. Phrases such as my partner 'takes care of me,' 'takes interest in my diabetes,' 'supports me' and 'adapts to my needs' were much more likely to come from males.

I have a lot of support from my wife, I find a lot of support from my wife… that is all I have got to say […] she helps me control [my diabetes] when she cooks for me, because I do not cook. She cooks what is good for me and she never tempts me to eat sweets and this sort of thing, never. […] I cannot complain; I receive a huge amount of support from her. (Clyde, 50FG)

Two male participants stated that their partners took so much interest in their diabetes care that it was as though they themselves had the condition. On the other hand, support provided by male partners was more likely to be related to specific aspects of care; it was practical and episodic, rather than continuous. Female participants were more likely to use phrases such as 'takes care of me during a hypo,' and 'reminds me of my medications,' when referring to support received from partners.

7.3.2   Property: Family as disabling

Individuals generally spoke of being supported by their family in one way or another, but there were a number of reported ways by which elements of support could be missing. In general, family hindered self-management because of their traditions related to food; with the way they pressured participants to comply with recommendations; and through traditional roles participants held in family care. Related findings are presented in the sections below.

Family was perceived as disabling when, due to food-related traditions, family members brought tempting, 'prohibited' food to their immediate access. This happened, for example, when sweets were kept at home because of other family members, including grandchildren who are traditionally given sweets. Sweets at home were perceived particularly tempting during festive seasons celebrated by traditional food, such as Christmas cakes, *figolla* for Easter (a traditional pastry with an almond filling) or *prinjolata* for Carnival (a cone-shaped assembly of cake, almonds and fruit, topped with cream and pine nuts). It is still common for Maltese housewives to cook such treats on these occasions and to cook enough portions to give away to friends or family. Eating with family members who ate different food,

which was more appealing to theirs, also proved to be challenging. A male participant said he always ate on his own because of this issue.

Many participants reported being hindered by family members when they pressured them to adhere to dietary recommendations. These members would pass comments whenever the individual with diabetes ate something which he/she ought not to, in an attempt to stop this behaviour. These situations were interpreted differently. Some would see the action as well-meaning, and would view it positively. However, most of the discourse about this action was negative. Family members who exerted pressure were often referred to as 'getting on my nerves' or 'irritating me.' They felt as if their family members were 'intruding' in their diabetes management.

> The fact that they keep telling me "Don't eat this" and "Do that" and "Now not this" and "Now not the other"… I don't want anyone to pester me about these things. I know my own business and if I want, I do them and if not … (Helga, 60FG)

A good number of individuals felt as if they were being reprimanded when others commented on their actions. As such, they felt as if they were being treated like children. Those around them seemed to fail to acknowledge them as responsible adults.

> And even me, especially if there is my son, near me [at a wedding reception], because I have a son who watches over me like a hawk, he starts telling me, "Are you going to do it again [taking sweets/food]?! Are you going to do it again?!" And it feels like you are sort of being scolded all the time, like a young girl. (Sue, 60Int)

Feeling treated like a child elicited a childish response from participants, who often reported eating restricted food, such as chocolate, behind the backs of their family members. Sometimes the intrusive, reprimanding remarks of others would be so annoying, that, like children they would become vindictive (with food) when the other family member leaves the scene. In fact, many participants reported that this behaviour from family members made things even worse.

There is an element of being rebellious […] this sometimes causes tension to build up within you, sometimes you wait for her [wife] to leave and you become extremely self-destructive, I would start from the first [food item] and go on [eating], seriously! [....] It [rebellion] is within you. One tells you to do this, the other tells you to do that, it is like when you are at school, as soon as the teacher leaves, you start doing [what you want] .... (Roderick, 60FG)

Finally, female participants' attitude towards their role as family carers, was also seen to hinder their diabetes management. Female participants felt constantly obliged to put family first, in their thoughts and actions. This was construed as making life with diabetes harder in a number of ways.

Females constantly worried about and felt responsible for the needs of other family members. A number of women reported worrying about their husband's diabetes and his non-adherent behaviour. They felt they needed to care for their husband's diabetes over and above their own and this would stress them. A young, married female participant worried about her father's diabetes and she spoke about him more than she spoke about herself during the focus group. None of the male participants were noted to speak about their wife's diabetes.

Females also put family first when they cooked. While male participants often reported having their wives cook food which was suitable for them, female participants tended to cook according to what family preferred. Usually they would carry out adjustments to their portions during food preparation, such that their meal would be more suitable for diabetes. Sometimes they would not even make such adjustments. They would prepare exactly the same food as their family's and would either eat it as it is, or eat selected items of it. Women generally did not expect their family to adapt their eating patterns to their diabetes-related needs.

For example [when I cook] quiche lorraine, I cook for everybody and then I remove the pastry [from my portion]. *I have to adapt to them, they can't adapt to me* because the kids would not want vegetables, my husband would, but I cannot hassle myself preparing food for me, food for my husband and food for the kids. *Forget it, I can't.* (Nadine, 50FG)

For a number of female participants the idea of caring for family, including grown-ups, meant doing things for them. This would include grown up kids and husbands, who would in the process become dependent on the wife/mother for various activities. In fact, a good number of male participants reported that their wives prepared their medications. This attitude tied females down and kept them too busy to care for themselves, as seen in the excerpt below quoting a female participant with grown-up children.

> How can I leave [my family] to go for a walk? That is what my husband does, when he decides to go walking, he goes walking, but I cannot decide to go walking [….] I get up at four in the morning [….] They [my husband and children] have to go to work, [and] I need to wake them up for work, I need to prepare their lunches, how can I [go for a walk]? (Susan, 50FG)

Female participants sometimes complained of being too busy with family care and general household chores, in order to take care of their diabetes. This was especially so with working mothers. While the issues of wanting to do things for others may be one important reason, the way that partners divided household chores between them might also have contributed to this. A few female participants, such as Sandra (see excerpt below), complained of having little or no help from their partners in housework.

> My husband does not help me. I have no help at all from him with regards to household chores. I am telling you, we would eat and he would not even remove his glass from the table. [….] Besides working, I have to do all the housework. [….] [He does] nothing, for example [he would] not even help with my daughter or this sort of thing, I have to do everything. (Sandra, 18Int)

There were a few male participants who reported not having sufficient time to care for their diabetes, but this was never attributed to family care or household chores, but rather to the demands of their job. The process by which family was seen as being enabling or disabling is represented in Figure 7.3.
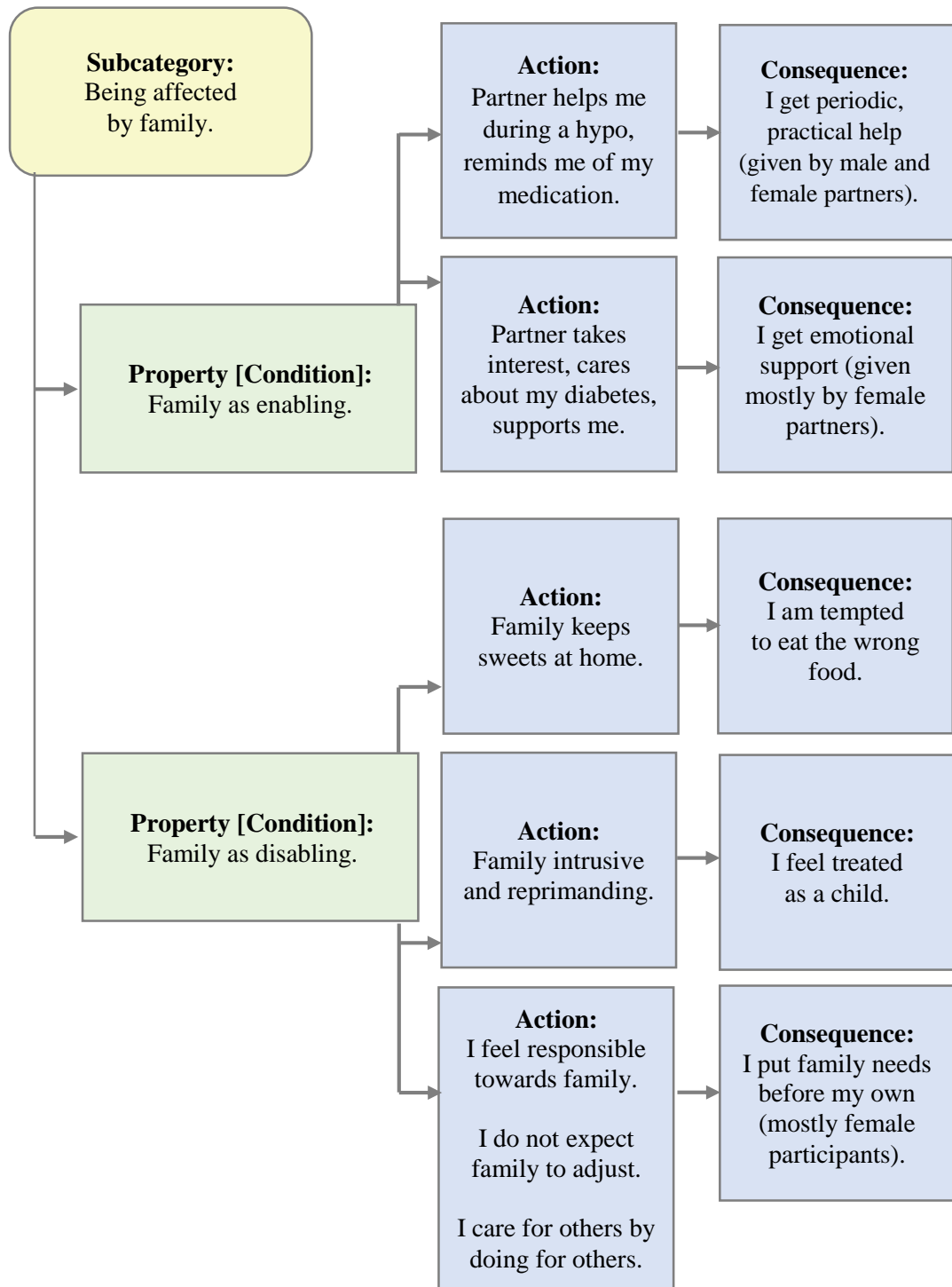
Figure 7.3 Issues surrounding the effect of family on diabetes self-management

7.4   Summary of findings

This chapter featured everyday experiences of living with diabetes in a Maltese society. A minority of individuals felt that in the public eye, diabetes is demeaning and renders the individual as different, weak and inferior to others. There were also those who felt judged and discriminated against because of their condition. As a reaction to such beliefs, these individuals avoided disclosing their condition to others. Nonetheless, disclosure was not always a choice and environmental factors often imposed disclosure. For those who avoided disclosure, living with diabetes seemed to be a more serious challenge. These participants had to adapt their behaviour, not only in a way which helped them control their condition, but also in a way which enabled them to hide it.

Family was viewed as affecting diabetes self-management in different ways. When family members offered practical help with diabetes-related care and instilled a sense of interest in such care, they were construed as being helpful. However, family could hinder diabetes self-management by increasing the presence of tempting food or by interfering with self-management, thereby undermining individuals' ability to act responsibly towards their diabetes. Male and female participants were affected differently by family with female partners being generally perceived as being more supportive than their male counterparts. The influence of family on female participants seemed to be partly related to their attitudes towards their own role as family carers.

Part 2   Discussion of findings

7.5   Introduction

Findings related to social stigma and family will be discussed in this section with reference to Maltese and foreign literature in these subject areas. As previously mentioned, another topic to be discussed is the influence of Maltese food culture on diabetes self-management. Reference has been made to this subject in various sections so far in this study, highlighting how at times, food-related traditions and practices made life difficult for participants. Since food culture makes up an important component of the social environment, it will be discussed in greater detail in this chapter.

7.6   Diabetes-related stigma

Feeling stigmatised because of diabetes was one of most challenging experiences amongst some participants. Stigma had an overwhelming negative impact on how these individuals felt that they were viewed by others and it shaped interpersonal behaviour accordingly. Before discussing this subject further, the following section will place the issue of diabetes stigma within the Maltese cultural context, which undoubtedly affected not only the stigma experience amongst participants, but also the quality and quantity of related data which could be collected for this study.

7.6.1   Diabetes-related stigma within the Maltese culture

Although no literature could be traced about the origins of diabetes-related stigma in Malta, factors such as those characterising the Maltese language, point to this problem as having been around for years. For example, while there is a well-known technical term for diabetes in Maltese, *diabete*, Maltese people have always referred to this condition as *zokkor* meaning 'sugar,' such that individuals are asked whether they have 'sugar' rather than 'diabetes.' This was noted by a participant, as being somewhat degrading. In fact, the term *zokkor* is only used colloquially and not in formal communication. Long-standing classical jokes in the Maltese language also feature a degrading attitude towards diabetes. For example, when someone looks for

something and experiences difficulty with spotting it, it is usual for others to teasingly ask whether he/she has 'sugar' in his/her eyes "*mela ghandek iz-zokkor f'ghajnejk?*"

The perpetuation of diabetes stigma in modern Maltese society is enhanced by referring to diabetes as a national or community 'burden.' Causes of diabetes-related stigma could also originate from epidemiological factors. As mentioned earlier, since diabetes is common in Malta and due to its small size, most citizens are likely to have a relative or friend who has suffered from diabetes complications, rendering the mental representation of this disease amongst the population, as one which is associated with serious disability.

Factors mentioned above indicate that diabetes-related stigma is therefore prevalent amongst the Maltese, an issue which only a small number of individuals in this study mentioned during interviews. However, observations indicate that stigma may indeed be experienced by more than a minority of individuals with diabetes in Malta. As shown in the first part of this chapter, individuals affected by stigma tended to avoid disclosing their condition to others, which in itself may have deterred individuals from accepting to participate in focus groups, fearing that they might meet someone they know at the group meeting. In fact, this happened several times during the data collection period. This means that individuals participating in this study were likely to under represent those who were affected by stigma. Also, during focus groups, it was evident that some individuals were reluctant to discuss stigma and admit to being affected by it. They would either avoid answering related questions or speak about stigma using the third person, not to personalise the issue. It seemed as though being concerned about stigma and avoiding disclosure was perceived as a weakness. Feeling stigmatised meant acknowledging being marginalised because of diabetes, a notion which not everyone was comfortable discussing in the 'public' context of a focus group. In fact, at times there seemed to be group pressure towards denying feelings of being stigmatised. Consequently, I approached those individuals who were affected by stigma to be re-interviewed on a one-to-one basis after focus groups, in order to explore related experiences.

While these factors were likely to influence the quality and quantity of data collected about stigma, it is important to note that none of the participants in this study had overt disabling complications, such as amputations and blindness which might have intensified the stigma experience. This could also have influenced the nature of data collected.

The social process by which chronic illness is stigmatised has been studied across different cultures. In the next section, related literature will be compared to findings of this study.

7.6.2 Social construction of stigma and its influence on diabetes-related experiences

This section will discuss the process by which stigma is constructed by societies. Evidence about diabetes-specific social stigma is scarce and has mostly been obtained from qualitative studies examining the general experience of living with diabetes. Consequently, most of the literature which will be used for discussion is that originating from psycho-social theories of stigma, including the seminal work of Goffman (1968), as well as literature related to stigma in chronic illness.

In this study, stigma-related experiences were found to be deeply unsettling. Sometimes, this issue was much more concerning than any aspect of diabetes self-management. For example, for some participants, the biggest concern about dietary non-adherence, was not how this affected their glucose control, but rather, how this influenced the way others would judge them in relation to their behaviour. As stated by Stuenkel and Wong (2013), sometimes the burden of stigma of a particular disorder is far greater than that caused by the disorder itself. Communities initiate the stigmatising process when they opt to label, judge and discriminate against the individual with chronic illness. There is general consensus that these social behaviours constitute the three basic components of the stigmatising process (Jones & Corrigan, 2014) and each will be discussed in the following sections with reference to how they affected the life of participants in this study.

7.6.2.1 Labelling

Participants who felt stigmatised spoke of how society thought about them as being weak, unhealthy and restricted. They were perceived as different from others in both their physical abilities and their behaviour. These accounts feature a labelling process, whereby marginalised groups are considered different and inferior to others. According to Goffman (1968), the labelling of individuals as 'deviant' by powers of society, is central to stigma. Individuals are perceived as deviant when they act or look different from that which falls within societal norms. Such differences can include not only physical characteristics but also aspects of individuals' personality such as a weak will (as opposed to having a strong will as is expected by society). Goffman (1968) continues to state that such labelling is deeply discrediting. In fact, participants in this study who felt stigmatised, viewed themselves as devalued. These degrading behaviours have been shown to have a negative impact on self-perception. For example, in their qualitative study amongst Dutch participants with Type 2 diabetes, Kato *et al.* (2016) noted that upon internalising stigma (that is agreeing with it and applying it to themselves) their participants developed a lower sense of self-worth.

The labelling process is often associated with stereotyping which involves categorising individuals who share a particular discrediting attribute, such as chronic illness. These individuals are considered to share common characteristics. For example, as found in this study, those categorised within the 'diabetes' label were all assumed to be weak, restricted in behaviour, and not able to give 100% output at their place of work. Thus, as stated by Goffman (1968, p. 15), society constructs a stigma theory, by labelling and stereotyping in order "to explain the inferiority of the person, based on various assumptions related to the stigmatising condition." Stuenkel and Wong (2013) refer to the process of categorisation and stereotyping as a measure used by society to simplify life. Through this process, society would not have to decide what to do with every individual situation, but rather it responds to categories of situations. For example, responding to an individual with diabetes may be ambiguous until he/she is placed within the category of diabetics, which then makes it easy for society to predict his/her limitations and respond accordingly. Unfortunately, as Stuenkel and Wong (2013) point out, using stereotypes to

understand and guide response to individuals, decreases society's attention to other positive characteristics.

Concern about labelling and stereotyping was found in other studies amongst individuals with diabetes and across various cultures. For example, Morris *et al.* (2006) found that their participants from the UK felt defined by their diabetes and more recently, UK participants in Winkley *et al.*'s (2015) study said they refused to attend to structured diabetes education sessions because of shame and stigma related to their condition. In their study amongst Australian participants with Type 2 diabetes Broom and Whittaker (2004) found that these participants hated when they were treated 'differently' because of their condition. Amongst non-western cultures, Abdoli *et al.* (2013) who studied Iranian participants with Type 1 diabetes, found stigmatising attitudes similar to those found in this study. Their participants were concerned with being labelled as sick, disabled and deprived of a normal life and were considered as unlikely candidates for marriage.

The feeling of being different and discredited by others, tended to make participants increasingly sensitive to how members of their community behaved towards them. Being judged by others was perhaps the most concerning response. This is highly related to stereotyping as mentioned above and will be discussed in the following section.

7.6.2.2   *Prejudice*

Participants who felt stigmatised were concerned not only by what others thought of them, but perhaps even more, by how others reacted towards them upon such thinking. Participants resented being pitied because of their diabetes and others felt vulnerable to social insult, interpreting forms of communication in their presence, as malicious teasing. Participants' reaction to these interactions may reflect heightened sensitivity toward other's behavioural and attitudinal response towards their condition. In line with this argument and with reference to the chronic illness experience, Charmaz (1983, p.190) writes how individuals "scrutinise encounters with others for hints of discretisation and negative reflections of self." She writes that not only do individuals with chronic illness become increasingly sensitive to the

intentions of others towards themselves, but they also begin to interpret "actions of others in new and self-discrediting ways and thereby increase their own suffering."

Personal suffering was evident mostly when participants experienced judgemental attitudes towards them. Participants felt judged when they did not adhere to their diabetes regimen or when they were considered guilty for bringing diabetes upon themselves. This chapter has presented examples of judgemental responses from family or friends. The next chapter will further explore this issue with reference to prejudice amongst health professionals who were reported to be too hasty to label their patients as non-compliant when their blood glucose was high.

A number of authors argue that prejudice towards individuals with diabetes originates from the fact that diabetes is a 'lifestyle' disease and hence considered as self-induced (Broom & Whittaker, 2004; Stuenkel & Wong, 2013; Jones & Corrigan, 2014). As Broom and Whittaker (2004, p. 2372) point out, diabetes is considered as a "disease of excess suffered by those who have over-indulged" and this is because they lack self-control and fail to assume responsibility for their health. Jones and Corrigan (2014) consider these views as stereotypes which make people develop negative affective attitudes towards those with diabetes. This may, in turn, affect public expectations, such as presuming that individuals with diabetes should comply with recommendations. This explains why participants in this study felt judged when they failed to adhere to their dietary regimes. Stuenkel and Wong (2013) further argue that, in the eye of the public, these stereotypes render individuals with diabetes less worthy of help. In this regard, the authors compare diabetes with other self-inflicted conditions, such as alcoholism and drug abuse. Tak-Ying Shiu *et al.* (2003), who draw upon two qualitative studies carried out amongst Hong Kong Chinese individuals with diabetes, report how participants in these studies experienced unfair treatment due to the perception that they unfairly utilise societal resources as their condition is less worthy of services than other 'more legitimate' medical conditions. In this present study, it was noticed that as a result of such stereotypes, individuals with diabetes actually lowered their own expectations from health services. They felt undeserving of good quality service in view of their irresponsible behaviour. This is a unique finding which will be presented in the next chapter.

Prejudice, while being a problem on its own, further complicates the life of individuals with diabetes as it leads to discrimination. This will be discussed in the following section.

7.6.2.3   *Discrimination*

The issue of discrimination was only brought up by two participants, and although this does not render the subject area unimportant, it is the reason why this topic will only be briefly discussed in this section. Discrimination resulting from diabetes-related stigma is also scarcely addressed in the literature, although there is evidence which shows that it exists.

In this study, discrimination was related to employability, whereby a male participant felt that individuals with diabetes in Malta would have problems with getting a job or retaining employment, if they disclosed their condition to their employers. This did not only affect the individual's disclosing behaviour, but made him reluctant to request conditions of work which enabled him to manage his diabetes. This trend is very similar to that reported by participants of other qualitative studies, such as those involved in the study by Broom and Whittaker (2004) who were concerned about the impact which their diabetes might have on their employment, for which reason they chose to keep their diabetes undisclosed amongst fellow workers. Vermeire *et al.* (2007) report similar results in their meta-synthesis of multi-national studies amongst individuals with Type 2 diabetes, whereby in a Slovenian study, participants considered diabetes as a stigma in the business world in which one had to be healthy and perfect. Quantitative data, which shed light onto the size of the problem, was produced by the second Diabetes Attitudes, Wishes and Needs (DAWN2) study. This was carried out in 2011, using a cross-national approach, involving 8596 individuals with diabetes across 17 countries. It examined diabetes-related psychosocial outcomes for people with this condition and revealed that one in five participants with diabetes felt discriminated against because of their condition. These individuals reported more problems with living with diabetes, less perceived support and a reduced sense of well-being (Kalra & Baruah, 2015). Problems related to well-being were also reported by Potter *et al.* (2015) who, in their quantitative study amongst individuals with Type 2 diabetes,

found self-reported discrimination to be associated with higher levels of diabetes-related distress.

This section has discussed findings related to the central components of the process of stigmatisation, all of which were found to compromise one's ability to successfully adapt to life with diabetes. Being fully aware of these consequences, a number of participants opted to avoid disclosing their condition to others. Although this may have reduced their risk of being stigmatised, it still instilled certain anxiety and adversely affected self-management. These issues will be discussed in the next section.

7.6.3   Reactions to fear of stigma: Choosing not to disclose

For fear of being labelled, judged or discriminated against, participants chose to disclose their diabetes only to close friends or relatives. Goffman (1968) refers to the act of avoiding disclosure, as managing one's identity through selective disclosure of personal details and Stuenkel and Wong (2013) describe this as a coping mechanism of secrecy and withdrawal. Both these authors point to the effect which selective disclosure may have on social networks, not just by reducing their size, but also by affecting their quality. For example, in this present study, Alex, a male participant met a work colleague at a diabetes educational event and it was there that this person became aware of his condition. He immediately expressed his disappointment about not having been previously informed of Alex's condition. Discovering the truth and the fact that this had been withheld from him, created a tension between them. The individual with diabetes thus often lives with constant anxiety lest his secret is discovered.

Besides 'not telling' about their diabetes, individuals in the present study reported avoiding behaviours which would give them away. These included tablet taking or going to educational classes in their community. Others would carry out the behaviour but in a way which would preserve their managed identity. This could mean taking tablets at their place of work when others were not looking, or in the bathroom. Similar behaviours have been reported in studies carried out amongst other cultures. These include avoiding self-testing in public and making unhealthy

food choices in social occasions due to reluctance to decline what was on offer (Spenceley & Williams, 2006; Schabert *et al.*, 2013).

Such approaches towards avoiding disclosure seem to directly or indirectly influence self-management, either through the action itself (such as skipping medication at work) or through the anxiety which the action produces. This has been frequently discussed in the literature. For example, Jones and Corrigan (2014) write how selective disclosure may lead to increased stress and anxiety about accidental disclosures and frustration from its impact on interpersonal relationships. Schabert *et al.* (2013) in their review of literature and Braitman *et al.* (2008) in their study amongst European American participants with diabetes found that avoiding disclosure could compromise self-care, sometimes as a result of its impact on emotional well-being. Overall, as expressed by Broom and Whittaker (2004, p. 2381), keeping diabetes a secret, seems to "inadvertently undermine the agency of people who are already coping with a demanding discipline and a potentially disabling disease." In this present study, this could be better understood when comparing the experiences of those who avoided disclosure with those who were open about their condition. Amongst the latter, being frank about their condition not only enabled others to understand their 'anti-social' behaviour during parties, but they would actually support it, such as through preparing appropriate food at parties/barbeques. To this extent, disclosing diabetes with friends became a form of proactive coping, whereby the individual would enable others to support his/her dietary regime in an otherwise problematic circumstance.

Although the issue of stigma in chronic illness and the avoidance of disclosure as a reaction to it, seem common amongst different cultures, unique to this study was the finding that individuals sometimes lost control over disclosure mostly, though not exclusively, as a result of the geographical characteristics of Malta, which made hiding one's condition problematic. The risk of involuntary disclosure created a constant suspicious feeling amongst participants that the people whom they came across would know about their condition, even if they would have never told them about it. This was likely to cause constant anxiety and problems in relationships similar to those mentioned above. Participants were even more frustrated when involuntary disclosure happened as a result of insensitive practices and an

inappropriate environment such as with the local, often small pharmacies, where maintaining confidentiality about one's condition is often difficult. This evidence shows that while stigma related to diabetes caused substantial hardship amongst Maltese participants, these were highly limited in their ability to avoid its disclosure as a coping strategy. In view of the limited literature in this subject area, more research is needed to examine the cultural and geographical impact on this problem and the influence this has on self-management.

7.7   The family

'Family' featured highly in all interviews and discourse about family highlighted the strong influence which it had on diabetes self-management. Overall, family influence was complex and was often determined by cultural factors and family traditions. In this section, reference will be made to literature about the influence of family on diabetes self-management, a topic area which has been widely studied across the world and which accentuates the central and yet different role of family in self-management across cultures. Before proceeding to this discussion, the culture of the Maltese family will be outlined with reference to Maltese literature. Unfortunately, recent work on Maltese families could not be traced and the literature presented here may not reflect newer trends in family values, such as those brought about due to the introduction of divorce legislation in 2011.

As stated by Gambin (2001), women's liberation movements have spurred changes in family values, which have challenged definitions of the female role within families. The Maltese family has also been affected, although the change was not radical compared to the global scenario (Gambin, 2001). In fact, as Rizzo (2006) writes, the traditional demarcation between gender roles in families is still generally held in Malta, with males being the main breadwinners and females the main family carers. Today, this is still generally the case as reflected in the low rate of female participation in the workforce which stood at 40.6% in 2015 (NSO, 2016) being amongst the lowest rates in the European Union (EUROSTAT, 2016). In a study carried out by Baldacchino (2003) reasons given by mothers for not working reflect their beliefs in the value of raising one's own children. Borg (2006) writes how, with the persistence of traditional roles, Maltese mothers are still expected to take up

a disproportionate amount of family responsibilities and this is considered by Abela *et al.* (2005) to be an important source of self-esteem amongst Maltese mothers. However, as Cutajar (2009) states, the fact that caring is still perceived as a feminine role has impacted negatively on women's paid economic activity rates.

Abela (2009) describes the Maltese family as being a modified extended type. She refers to the fact that many married couples live in the same town or village as one or both of their parents and she writes about the custom that children only leave their parents' house on their wedding day (a custom which is declining, but still highly prevalent). Gambin (2001) also refers to how women maintain a close relationship with siblings, grandparents and other relatives after marriage. This has also been highlighted more recently by Baldacchino (2011) who considers them to be persistent traditions characterising a Maltese family which holds both nuclear and extended family traits. The small size of the island is an important factor in helping these traditions to prevail. Thus, though family values may have 'modernised,' cultural practices have lingered on and this seems to be reflected in data of this study. It is important to note that this study's findings about family may also have been affected by the fact that only a small minority of families represented in this study were young. As stated by Cutajar (2009), although the Maltese family has undergone significant social change, this is more apparent amongst younger families.

The next section will discuss the supportive role of family, followed by a discussion of how at times, family was also perceived to hinder self-management. The influence of gender will be discussed throughout.

7.7.1 Family as supportive to self-management

For most of the participants, family was construed as being central to supporting self-management. Other qualitative studies amongst various populations also found participants to view family support as a key factor in diabetes self-management. Examples of such studies include those conducted by Furler *et al.* (2008) involving Australian participants, Hasseler *et al.* (2011) with German participants and in the case of Nguyen and Edwards (2014), Vietnamese Americans. These studies utilised a qualitative design, gathering data from focus groups or in-depth one-to-one

interviews. Hasseler *et al.* fail to back up the researcher's interpretations by related participant data/quotations, this having an adverse impact on credibility of findings. Quantitative studies have also shown the positive impact of family support on self-management behaviour. Rintala *et al.* (2013) refer to such studies in their systematic review of literature about the influence of family on diabetes self- management. Studies included in this review found family support to be associated with better self-management practices. A limitation of this review is the lack of quality assessment of the studies involved.

While the importance of family support in self-management is a widely held view, a unique finding in this study was the fact that support received by male and female participants was different. Male partners tended to provide episodic, practical support, while female partners, topped this up with giving emotional support to their husbands with diabetes. This finding supports the general notion that women tend to be more caring and nurturing than men. According to Seppala (2013), this may indeed reflect different ways by which men and women are socialised into their separate roles and does not reflect any innate differences in ability to care and nurture. Giddens (2009, p. 601) refers to this as the "learning of gender roles," which is brought about with the help of social agencies, such as the family and the media. This nature versus nurture argument is indeed still a highly debatable issue. The persistence of gender-related roles in Maltese families, where women tend to take responsibility of the emotional well-being of their families (Abela, 2009) may also explain this difference in support provision between male and female participants.

Despite perceiving and appreciating family support, participants pointed to instances when family actually hindered self-management. This is explained in the next section.

7.7.2 Family as a hindrance to self-management

According to participants, family could hinder self-management in a number of ways. This would either be due to the role of food in family life, to the controlling behaviours of certain family members towards participants, or the actual roles which

participants assumed within family. The way in which these issues impacted on self-management will be discussed in this section.

Family traditions in relation to food, including the way Maltese family showed respect through food, celebrated with food and maintained family unity through food, all contributed to making restricted food more accessible and hence, more tempting for participants. This was perhaps, the simplest way by which family hindered self-management, but for some, this was what made self-management most difficult.

As mentioned in Part 1 of this chapter, in line with family traditions, individuals kept sweets at home, and participants, knowing that they were stored in cupboards, considered this as a constant temptation. In fact, according to a male participant, dietary problems could only by resolved if and when he would live on his own as he would then have complete control over what was kept in the house. Quantitative research conducted by Portelli (2014) has also shown that Maltese families give priority to meal preparation and set eating hours. This reflects a ritual tied to eating and with having all family members present during meal time. Participants of this present study referred to problems this caused since during meal times other family members often ate different, more appetising food than theirs. For this reason, a young participant said he preferred going against tradition and eating on his own. Some of the challenges brought about by these family traditions involving food, are particular to Maltese culture.

While the culture of food and family made it difficult for Maltese participants to stay away from restricted food, family also tried to make sure that the rules of restrictions were abided to. However, this in itself became problematic. Participants complained of the way family sometimes exerted pressure on their dietary management. Family members constantly watched over what participants ate and attempted to stop them when this was inappropriate. Participants often interpreted this behaviour as intrusive and regarded it as a failure by their family to treat them as responsible adults. They felt that it was their responsibility to comply with recommendations in order to control their diabetes and they expected others to respect this autonomy. This is reflected in how Helga, a female participant, asserted

an individual rights discourse, claiming it was up to her to manage the way she felt she should (see excerpt in Section 7.3.2).

This issue of family pressure seems to be a common phenomenon which has been identified in other research work. In fact, I have failed to come across literature which challenges related findings of this study. Participants in other studies have also been found to interpret this behaviour as 'intrusive' (Morris *et al.* 2006, Paterson *et al.* 1998), or as unwelcome advice-giving (Samuel-Hodge *et al.* 2013). These last authors write how their African American participants felt overprotected by family who left them feeling powerless to make their own decisions in diabetes care. In this present study, the enforced powerlessness was often rejected by participants who felt demeaned and treated as children. They respond through behaving in a way that is contrary to the given advice. Though this may take the form of reclaiming adult status, participants themselves have considered this as rebellious childish behaviour. They felt further demeaned by their own childish response. This counterproductive effect of family pressure has been reported in other studies (Paterson *et al.,* 1998; Broom & Whittaker, 2004; Morris *et al.*, 2006). Samuel-Hodge *et al.* (2013) whose qualitative study included family members, examined these members' perspectives about this issue. They found that family members also felt that their well-meaning advice was not helpful and that it irritated their loved ones. However, although they hated to watch over their relative, they were concerned when he/she did not comply and felt compelled to say something about it. At the end they felt confused about what their role in these situations should be.

The last negative influence on self-management to be discussed in this section is strongly related to gender and seemed to render the illness experience amongst male and female participants significantly different. Data from this study has shown that the caring role taken by female participants towards family disadvantaged them, as it kept them so emotionally and physically involved in family life that there was little space left for them to look after their personal health needs. This is related to traditional gender roles in families, which persist within Maltese culture.

Female participants felt highly responsible for their family's welfare and concerned about their family's health, more so than males. This was reflected in how they worried about the diabetes of other members of their family, such as a husband or parent. For these participants, this was a constant source of stress. Reporting similar findings in their meta-synthesis, Gomersall *et al.* (2011, p.864) write that 'within a gendered context, self-management might be an oversimplified term and adding the meaningful term 'self-and-other-management' would arguably better capture women's experiences of managing diabetes.' In their qualitative study of African-American women Cagle *et al.* (2002) also found that these participants assumed a multi-caregiver role and that providing emotional and physical support to other members of their family detracted them from managing their diabetes. These women often had to face a conflict between responsibility to self and responsibility to others. A middle-aged female participant in this present study spoke of how everyday decisions had to be balanced between the benefit these would reap for her, as opposed to the damage or inconvenience they would impose on her family. An example of such source of conflict was when she baked a cake. She knew it would all be eaten by her daughter because both she and her husband had diabetes. She pondered about how unhealthy this would be for her daughter and she felt guilty about not sharing. Similarly, in their study amongst Brazilian women, Guerreiro Vieira *et al.* (2012) found that these women worried about and anticipated future threats to the well-being of family members and this was so pervasive that it interfered with their diabetes control.

Female participants in this study were not only concerned about assuming responsibility for family and the stress this evoked, but also about the time taken up by family and household chores which left little time for diabetes-related tasks, such as exercising or cooking the right meals. This is tied to another attitudinal issue amongst them. As found in a number of other studies, female participants did not expect family to adapt to their diabetes and this influenced what they cooked and what they ate. They cooked according to their families' desires and would eat the same, or slightly adapted meals, as they had no time to cook separate meals for themselves. This was found to be common practice amongst Iranian women (Shakibazadeh *et al.*, 2011), Sri Lankan women (Amarasekara *et al.*, 2014), Korean women (Park & Wenzel, 2013), and African American women (Cagle *et al.,* 2002),

showing how women in these non-western cultures subjugated their own needs for needs or preferences of other family members. This and other findings have pointed towards women's inclination to put family first in their decisions regarding their roles as mother, wife or daughter and in the process, they pushed aside their health needs. Gomersall *et al.* (2011) refer to this issue of prioritising on family needs as a trend within collectivist cultures, which emphasise family goals above individual needs. This trend thus characterises a socio-cultural expectation which acts as a barrier to self-management.

Despite showing how female participants were sometimes disadvantaged because of their roles in family life, this study did not explore whether and to what extent this differentiated self-management practices between genders. Notwithstanding this, inequalities in diabetes outcomes between genders have been repeatedly highlighted in various diabetes-related studies. For example, Chiu and Wray (2011), who measured various diabetes-related outcomes amongst 1,619 American adults, found that similar to evidence produced elsewhere, women had worse HbA1c levels, blood pressure and BMI, more frequent occurrences of early complications, reported lower levels of exercise, perceived poorer family support, had higher depressive symptoms and perceived more barriers to regimen adherence. As argued by Guerreiro Vieira *et al.* (2012) and as suggested by findings of this study, these illness patterns seem to transcend biology and include various psychological and cultural factors.

7.8   The influence of food culture

Participants construed food culture as having a significant impact on their diabetes self-management and examples of this have been referred to in different parts of this thesis. This section will discuss this issue, making reference to food-related experiences and connecting them to Maltese food culture.

Participants often graded their difficulty with diabetes self-management according to their ability to control dietary intake. For participants, control of food was the predominant feature of diabetes self-management and it often shaped their overall experience of living with this condition. For some participants, living with diabetes signified being deprived of the freedom to choose what to eat and how to socialise

with food and this challenged their very scope of living (e.g. see excerpt from Alfred, Section 5.4.1). These strong sentiments feature an experience with food which goes far beyond eating to sustain life. In fact, food amongst the Maltese has a strong cultural meaning which clearly influenced participants' diabetes-related experience. Such influence was found to be determined by two factors. First, by the way food is used by the locals as a means of socialising and secondly by the actual nature of the Maltese traditional cuisine. This section will discuss these issues.

In Malta, food features in every social gathering or celebrative occasion, such that these events proved challenging for participants. Social get-togethers at all levels involve food, including 'coffee mornings' and 'tombola' (bingo events) organised by Parish churches for senior citizens, and intellectual meetings at places of work. To this extent, in order to promote an activity, one is likely to include food and refreshments as an attractive component. It was partly for this reason that I included coffee and snacks during my focus groups. Furthermore, celebrative occasions such as weddings are synonymous with the indulgence of food and drink and participants, being expected to be present at these festivities, gave accounts of how they tried to participate with minimal repercussions on their diabetes (see Section 6.2.1). Sometimes, being selective in what to eat, would highlight their 'difference' from others who could celebrate freely. As some participants commented, one cannot keep saying 'no thank you' to food being offered without becoming conspicuous. Others opted to put their diabetes management on hold to fully participate in these events.

As stated previously, Maltese also like eating out with family on weekends and this had its own challenges. Besides the limited availability of healthy options at restaurants, a couple of female participants mentioned how their partners complained that they never joined them in the selection of exciting 'unhealthy' items from the restaurant menu. Diabetes turned them into 'boring' company to eat out with. Similar to this, a study carried out by Broom and Whittaker (2004) found that participants were reluctant to comply with their diabetes regimen during social occasions, as others complained of their 'impeccable' behaviour and saw them as spoiling social events. To this extent, socialising became comparable to a knife which cuts both ways. Opting not to participate in celebrative occasions meant

becoming 'an outcast' (see excerpt from Roderick, Section 6.2.1), while participating with limitations, to adhere to dietary recommendations, was sometimes perceived by others as being a spoil sport. Not all participants faced such issues, as some mentioned being highly supported by family and friends to retain dietary control during social occasions.

Diabetes management was also affected by popular food which forms part of the local traditional cuisine. Traditional Maltese food is heavily influenced by the healthy Mediterranean food culture, which is rich in fruits, vegetables and wholegrains (Cefai & Camilleri, 2011). Particular influence has come from Italian cuisine. Local food also has an Arabic influence, resulting from the long Arab dominion in Malta many centuries ago. In fact, as Billiard (2006) writes, the originality of Maltese food culture lies in the way it blends all foreign influences. While traditional food is still important in the life of many Maltese people, with typical Maltese dishes still featuring in the meals of an average household, the diet of Maltese individuals, is no longer highly characterised by that which is traditional. Rather, it is claimed to have become more westernised and largely influenced by a Northern European type of diet (Cefai & Camilleri, 2011). As mentioned in Chapter 2, the diet of the average Maltese today is high in processed meats, fats, sugar and salt and low in vegetables and fruit (Ministry for Health, the Elderly and Community Care, 2010). As Cefai and Camilleri (2011) note, this nutritional transition from traditional healthy diets to convenient and often fast foods has become common in many western countries. This has also affected dietary management of participants, some of whom, for example, mentioned eating fast foods for lunch. Nevertheless, some traditional foods, still featured highly in interviews, and were projected as having a significant impact on diabetes management. Two such examples of popular traditional foods are Maltese bread (*il-hobza)* and savoury cheesecakes *(pastizzi)*. The next section will explain how these traditional foods influenced participants' dietary management.

Pastizzi are considered to be the tastiest Maltese snack (Mitev, 2011b) made from ricotta or mashed spicy peas wrapped in puff pastry. It is also perhaps one of the most popular and is sold at many takeaway outlets and canteens and is the standard food item served in parties and social functions. *Pastizz*i are usually eaten as a snack

during the day, but are sometimes eaten to replace a meal. The problem with this snack is its high fat content (the traditional way of cooking this is using animal fat instead of butter). In fact, a single 100gr *pastizz* carries 416 calories (Mitev, 2011b). This renders this snack unhealthy and unsuitable for individuals with diabetes especially for those who are overweight or obese. Participants talked about how difficult it was for them to refrain from buying these snacks, particularly on smelling the nice aroma which they create near takeaways, when freshly baked. Some of them mentioned the standard practice of work colleagues who treated their work mates with this traditional snack during break times. A female participant described how these occasions highlighted her feelings of being 'different,' upon watching her workmates eat *pastizzi* while she sipped at her vegetable soup. In other words, the traditional use of *pastizzi* turned out to be one of the worst enemies for those who intended to be adherent to their dietary recommendations.

Il-hobza (Maltese bread), on the other hand, is considered to be a healthy food option, except for its slightly high level of salt. It is traditionally made from hand-kneaded sour dough which is shaped into a loaf and baked in wood-fired ovens (Kliewer, 2008). The outside of the loaf is crusty, while the inside remains very soft. Maltese bread is claimed to be the best in the world (Sammut, 2003) and it is so ingrained in the traditional Maltese cuisine, that it is referred to as the symbol of Maltese identity (Kliewer, 2008). Up until the present day, many homes have a fresh *hobza* delivered daily from the local bakery, including Sundays. Festivals dedicated to this local delicacy are held yearly, celebrating the culture associated with it. Maltese bread has various uses in the local diet. Nationals eat it as a snack, as an accompaniment to food, or as an appetiser. Because of the size of the Maltese loaf, and the way it is normally sliced, the weight of a typical slice of Maltese bread is almost twice that of a typical French slice. Thus, although the two types of bread have the same calories/unit weight, consuming Maltese bread may result in a larger intake of calories than consuming other bread. In fact, because of its high carbohydrate content, it is often suggested that individuals with diabetes limit their consumption of *il-hobza*, particularly if other carbohydrate sources are consumed. Also, because Maltese bread is made from refined wheat, it is suggested that it is replaced by wholemeal bread to attain a slower absorption of glucose. This supresses the cultural element of bread consumption and as such, proved to be

difficult for participants. During interviews they referred to *il-hobza* very frequently and it was actually mentioned 113 times across all interviews.

The fact that food culture influences diabetes self-management was a finding across a number of other studies, predominantly those carried out amongst participants of non-western cultures. These studies also found that both the social element of food, as well as the characteristics of specific cuisines tended to influence diabetes management. Gomersall *et al.* (2011) carried out a meta-synthesis of 38 studies to explore patients' perceptions of diabetes and they reported cultural influences across the studies. Asian, Latin and Mexican American participants were found to prioritise on the socio-cultural element of food over the dietary restrictions involved in self-management. Thus they would postpone illness management to take part in traditional celebrations involving food. This was similar to that found with some of the Maltese participants of this study who would put aside their dietary management to fully participate in celebrative events. Also, while participants in this present study talked about being seen as 'outcasts' or 'boring' when they failed to participate in social events, Gomersall *et al.* (2011) write how Latin and Mexican American participants who refused food or brought diabetes-appropriate alternatives to community events, were considered rude and unacceptable. Similarly, Korean participants in Park and Wenzel's (2013) qualitative study reported feeling obliged to accept food offered during social encounters as such sharing of food demonstrates respect and politeness in Korean culture. With reference to similar experiences amongst South Asians, Sohal *et al.* (2015, p. 7), refer to this phenomenon of social pressure as a 'competing cultural expectation' to dietary adherence. Gomersall *et al.* (2011) consider these issues as limitations imposed by collectivist cultures, whereby community norms and relationships take precedence over individual needs.

Studies, particularly those carried out amongst Asian populations, have also made reference to the influence of cultural cuisines on diabetes management. For example, Amarasekara *et al.* (2014) write that their Sri Lankan participants had problems with reducing their portion of rice and that alterations in the preparation of traditional food (such as not using the first extraction of coconut milk with curries) were not easily accepted. In their systematic review of diabetes-related studies, carried out among South Asian individuals, Sohal *et al. (2015)* also reported

difficulties encountered by these participants in adjusting their traditional diet which is typically high in saturated fats, mainly from ghee, milk and yoghurt.

7.9 The influence of the social environment on the emic DSMS

In order to connect this chapter with the previous ones, in this section I shall explain how the characteristics of the socio-cultural environment, as discussed in this chapter, could impact on the implementation of the emic DSMS (introduced in Chapters 5 and 6.) As mentioned in these chapters, for participants, self-management was construed to involve managing behaviour, by being **flexible** and **planning ahead** (being proactive) and managing thoughts by **preventing stress** and developing a **positive mind-set** (involving positive thinking and acceptance). Anything which helps or hinders these strategic measures is likely to determine how well the Maltese individual would cope with his/her diabetes.

Findings of this study indicate that diabetes-related stigma may be a significant problem, locally. Social stigma centres around perceptions of being different and inferior and in so doing it may instil negative self-perceptions amongst those who are labelled as such. This, together with feeling judged and discriminated against, challenges the development of a positive mind-set about having diabetes. Moreover, besides directly interfering with self-management practices (e.g. medication taking) avoiding disclosure was likely to cause anxiety and stress. The act of telling others about diabetes is in itself a way of establishing social resources for support. Such support could involve understanding and supporting diabetes-appropriate behaviour during social occasions. Thus, avoiding disclosure inhibits the use of such resources as a means of proactive coping.

In line with findings of other research, participants of this study found family support to be central to self-management. However, there were aspects of family life which rendered family problematic. For example, attitudinal issues among family members were viewed to hinder self-management, such as when they became intrusive. Besides causing family tension and stress, constant watchfulness and correction could leave little opportunity for the individual with diabetes to apply flexibility. The intrusion in itself could be a sign that family members do not

sufficiently understand the importance of flexibility and fail to support the autonomy which goes with it. Gender-related roles in family life were found to be of a disadvantage to female participants and this seemed to be common amongst non-western, collectivist cultures, in particular. These aspects were also reported to be a constant cause of stress for certain female participants and left little time for self-management. Finally, food culture in terms of both the national cuisine and food traditions imposed specific challenges to dietary control. The love for traditional cuisine and the social element of food left some individuals feeling restricted, different and unsociable, allowing little space for them to adopt a positive mind-set about having diabetes, when living in such a food-dominated culture.

As indicated above, findings suggest that the Maltese social environment could make it difficult for participants to implement the emic DSMS and this could adversely influence coping. This, however, would depend on the individuals' specific experience of the social environment. For example, individuals who seemed to cope well and to view diabetes management as 'easy,' were more likely to report positive social experiences, such as having family support. Female participants in this 'managing with ease' category were amongst the few who reported having supportive husbands and were able to prioritise their self-care needs, despite their family roles. Participants in this category were also less likely to be affected by stigma as they retained a positive outlook about themselves in relation to others and were thus more open to disclosure. However, even individuals in the 'managing with ease' category reported challenges related to food culture. For example, a male participant with good coping abilities reported being highly tempted to buy '*pastizz*i' when going past a takeaway outlet. 'Copers' also complained of having problems when eating out, showing how hindrances related to food culture applied to individuals across the board, even though their effect could be perceived at varying intensities. The way in which the social environment impacted on the implementation of the emic DSMS is summarised in Figure 7.4. Since Category 2 (presented in Chapter 6) illustrates the main components of the emic DSMS, this figure will link the environmental challenges as outlined in this chapter with elements of Category 2.
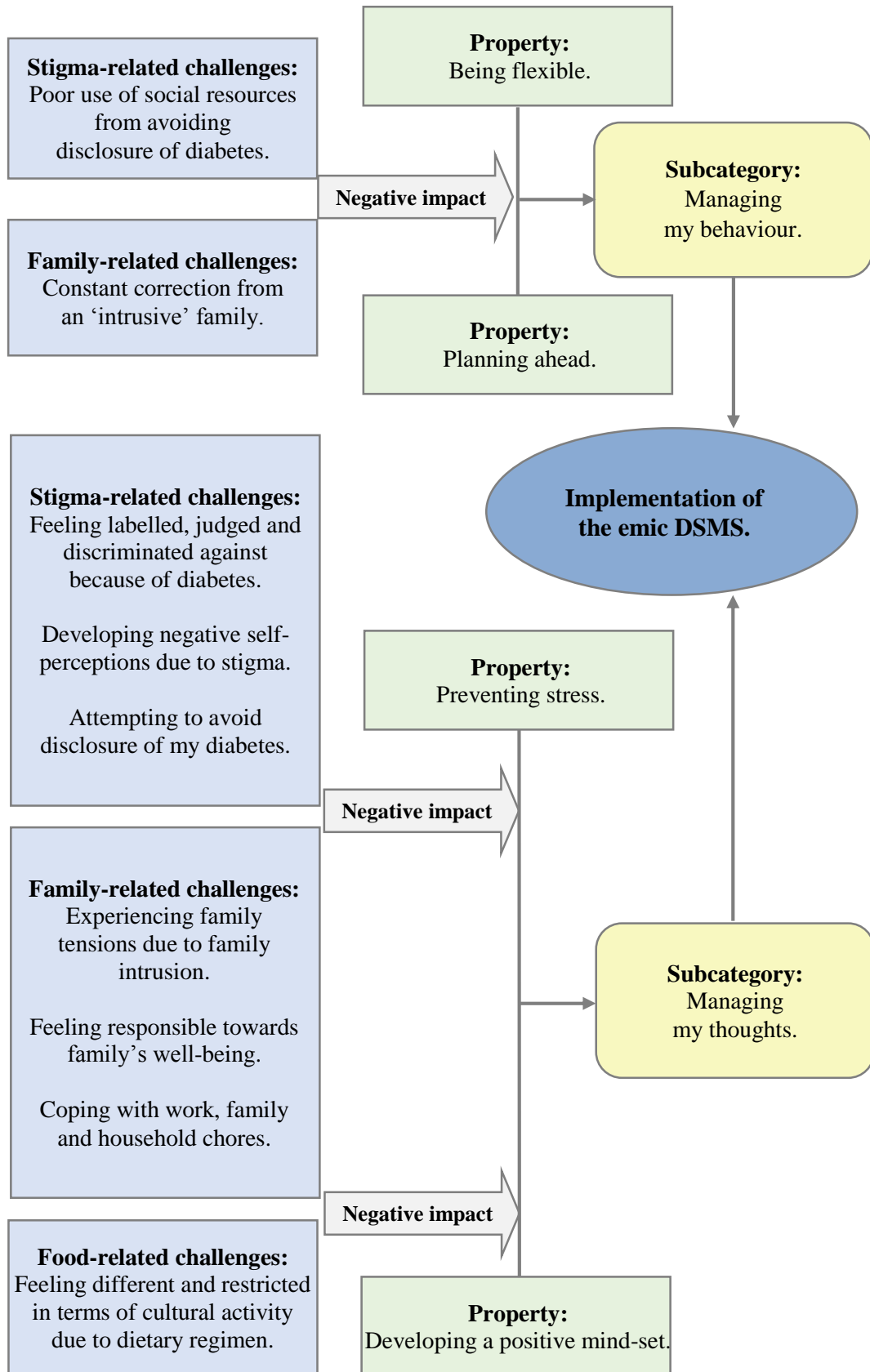
Figure 7.4   The impact of the social environment on one's ability to implement the emic DSMS

7.10 Conclusion

This chapter has highlighted the influence of the Maltese social environment on diabetes self-management. Findings have illustrated how Maltese people are characterised by their own way of life shaped around societal, family and food traditions, which in turn, are also influenced by the geography and history of Malta. This chapter has shed light into how these traditions and the underpinning values, influence diabetes self-management, and how they often impose significant challenges to such management.

Although the impact of various aspects of these traditions are similar to those found in studies conducted elsewhere, particular influences have also been identified. This highlights the potential uniqueness of the diabetes experience amongst Maltese individuals with this condition. For example, while social stigma related to diabetes is documental amongst various cultures, the inability to control disclosure about this condition as a coping strategy seems to render the stigma experience particularly challenging in Malta. Also, while the role of family in helping or hindering self-management is reported in various sources of literature, the influence from traditional family values which have perpetuated amongst the Maltese community, were found to create particular problems in self-management.

Individuals were found to experience the social environment differently, such that those whose experiences were positive were likely to cope better with their diabetes as they faced less challenges with implementing the emic DSMS. The next chapter will address further influences on participants' diabetes self-management.

Chapter 8

CATEGORY 4:
HAVING ACCESS TO CARE AND RESOURCES

Part 1: Findings

8.1   Introduction

The previous chapter addressed how aspects of the social environment were perceived to influence diabetes self-management in Malta. This chapter explores participants' views of the impact which Maltese health services had on their diabetes management. Participants perceived the supporting role of health services as being that of providing individualised follow-up care and resources required for self-management. However, the services which participants had access to did not always fulfil these expectations. This issue is addressed in the category 'Having Access to Care and Resources' which will be analysed and discussed in this chapter.

The first two subcategories presented in this chapter address the organisation of follow-up care and the relationship which developed between patients and their healthcare professionals during follow-up visits. The third subcategory is about resources which participants had access to in order to manage their diabetes. These findings are presented in Part 1 of this chapter and are then discussed in Part 2 of the chapter. Figure 8.1 gives an overview of Category 4 presenting its subcategories and their properties.
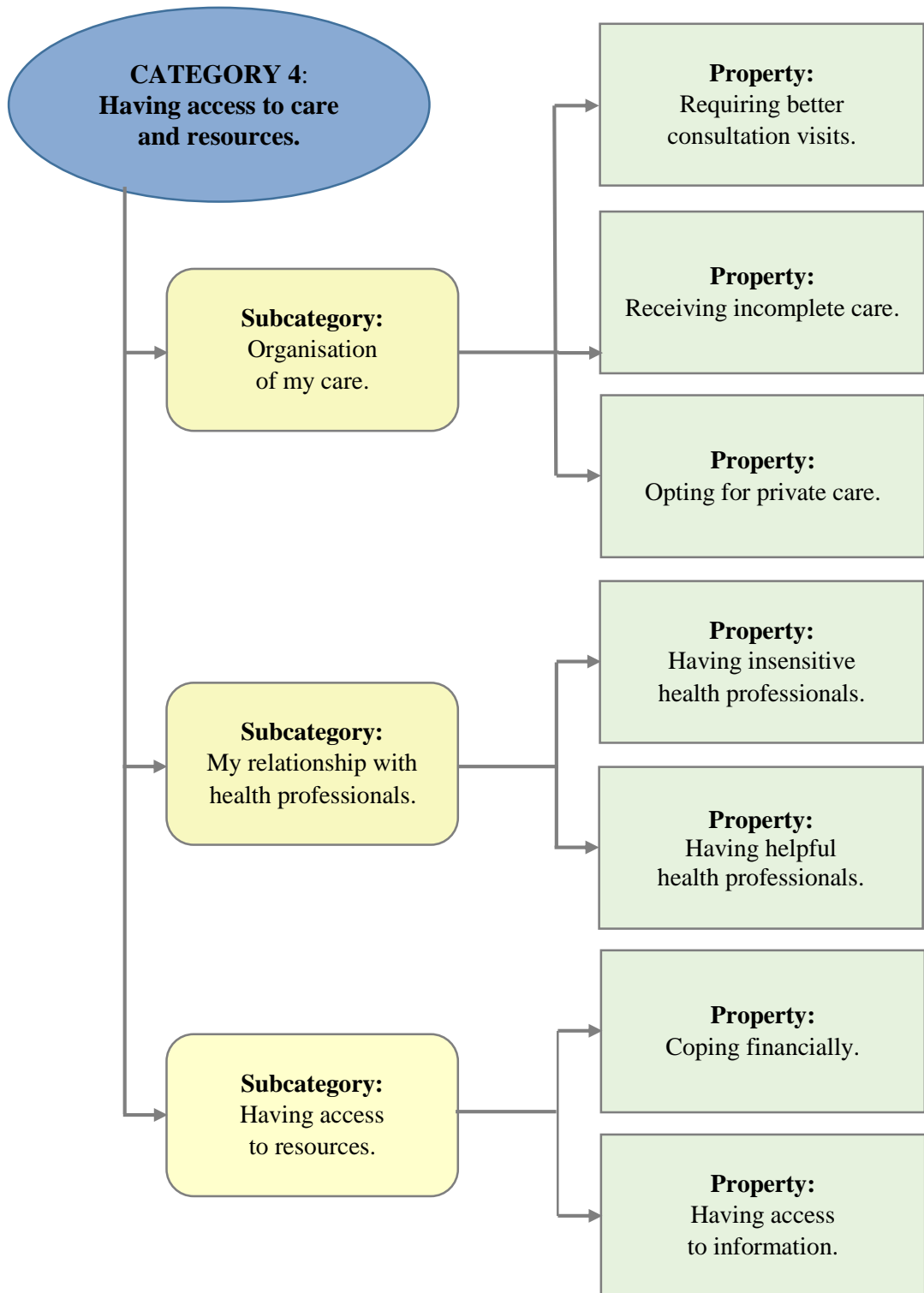
Figure 8.1: Elements of Category 4 including related subcategories and properties

8.2 Subcategory: Organisation of my care

This subcategory addresses participants' opinions about the way in which their diabetes follow-up care was organised. Follow-up care took place either at the Outpatients Department of the Mater Dei Hospital, or at community-based health centres. This care consisted of consultations with general practitioners (GPs) or diabetes medical specialists together with visits to other members of the inter-disciplinary team, such as podiatrists, who carried out further care and screening. Information about diabetes follow-up care in Malta was given in section 2.5.3, and more related information will be included later on in this chapter. Participants felt that follow-up care should support them to manage their diabetes and hence, they perceived it as being pivotal to their success in such management. However, as this chapter reveals, some aspects of the care received were viewed to be unhelpful.

The first property of this subcategory is about shortcomings in the organisation of the consultation visit with doctors, while the second property relates to poor organisation of follow-up care received from paramedical professionals. The third property is about private care which some participants accessed.

8.2.1 Property: Requiring better consultation visits

One of the most common suggestions for support provision was that of having more frequent appointments with GPs/diabetes medical specialists for follow-up consultations. Follow-up at health centres was reported to occur every six months and those attending the hospital clinic said they were given appointments with a gap of one year to eighteen months. The latter group of participants were the ones generally unhappy with the appointment system, although some of those who attended health centre clinics for follow-up wished to be seen every three months instead of every six. Participants feared that delayed monitoring of their diabetes due to infrequent appointments would result in untimely adjustments to their diabetes management.

Having very short consultations was another concern expressed by some participants who wished that doctors gave them more time during their visits. The average

duration of a consultation visit is not known. A common view was that doctors at the hospital/health centres were too busy and did not have enough time to discuss treatment options, give advice or to answer patients' questions.

> There is little time and therefore you wish that [the doctor] would talk more about diabetes. I don't know, perhaps he could give you some *hints*, helpful *tips* … Mostly, he just sees the blood results [and tells you whether] they are good or bad [and that's it] [...] You do not feel that he is ready to give you a little of his time to ask questions and talk. […] I am afraid to ask questions. I am afraid in the sense that I know he has no time … because you just get a flat answer ... in the sense, brief. He would show you that he does not have [time] that he has said enough. (Anne, 50Int)

Adrian, a male participant felt that by cutting his questions short, doctors showed reluctance to discuss management options and this was felt as if they were imposing their ideas upon him. Adrian considered the approach adopted in follow-up visits at the public health sector as being very impersonal.

> Maybe you have asked [the doctor] a question and perhaps it was a little controversial, for example, he would immediately [cut you short], do you understand, he would say, "No," […] "No you cannot do that." […] Doctors at the clinic sort of impose on you, […] that is, they do not give you time to discuss issues with them. [...] Because this is like a *production* line, a procedure, they do what they have to do and that is it. (Adrian, 50Int)

Adrian associated short visits to the fact that the service provided at the public health sector was given for free. He thought that possibly health professionals did not feel that their patients should expect any better.

Another issue of concern was that of being seen by different doctors/specialists during follow-up visits. Participants felt it was difficult for doctors to get to know them well during the one-off consultation and consequently, they were more prone to making mistakes. This caused participants to lose trust in decisions taken during these consultations.

> [the fact that you are seen by a different doctor] annoys you. OK nowadays, you just switch on the computer and it tells you my whole medical history, but I do not see it appropriate. Because if you are

always seen by the same person [doctor], he would get to know you better than another [doctor] who sees you just on one occasion. (Maurice, 60FG)

Being seen by different doctors with differing opinions on diabetes management led to inconsistent management advice. This provoked feelings of apprehension and confusion. Some doctors were reported to openly express their disagreement with other doctors' treatment decisions. This was construed as unprofessional behaviour and reduced trust in the medical profession. The following excerpt came from a participant who had been prescribed six Metformin tablets a day by a particular doctor. He explained the reaction of a different doctor who saw him during the next follow-up appointment and who believed that this dose was too high.

When I had an appointment, six months later, I was seen by another doctor, and as soon as he saw what I was taking, [….] he lost his temper [and said] "Why should they make you take these tablets? These [doctors] do not know what Metformin is all about!"... and "Why should they make you take this … and that?" [...] It seems as though not even doctors know what diabetes is all about and how they should treat it, because one [doctor] would tell you this, the other would tell you that and yet another might tell you something different. (Luke, 50Int)

Participants were not just unhappy about the organisation of consultation visits with doctors, but also complained of care given or not given, outside these consultations.

8.2.2 Property: Receiving incomplete care

Most of the participants were aware that they needed screening for complications, including eye and foot problems. Some participants received an annual check. However, a number of individuals complained of having infrequent or no eye check-ups at all. They would occasionally do these tests privately for this reason.

The Ophthalmic Section at the health centre have a problem. It has been about two years [since my last check-up]. In the past, they used to do it every year. Now I am having it done privately because they told me there is a long wait [for an appointment]. (Alex, 60FG)

This eye test they are talking about, is it the doctor who orders it for you? […] They never did the test for me. (Thea, 30FG) (This participant had been diagnosed with diabetes three years prior to the interview.)

Individuals who have had diabetes for years also reported never having been referred for a foot check-up. A few of them made an appointment at the foot clinic in health centres on their own accord and without referral.

Doctors were often reported to give little detail about nutritional management during consultations. They were said to be vague and general in their advice, such as suggesting that patients 'forget about having sugars' or that they lose weight. Also, some participants were never asked about their diet during consultations. At the same time, a good number of participants reported never being referred to a nurse, nutritionist or dietician for nutritional advice. Participants expressed their wish for better and more personalised nutritional guidance. However, the picture was not so negative for everyone. During her visits at the hospital clinic, a young participant reported being asked for details about her eating habits by her doctor who also recommended that she keeps a food diary. He/she would then give guidance accordingly.

8.2.3   Property: Opting for private care

In view of the shortcomings in follow-up care, 21 participants (over a third) sought private care, over and above that which they received from the public health sector. This was especially so for follow-up consultations with GPs/medical diabetes specialists. According to participants, at the private clinic doctors had more time to ask about their behaviour, listen to their problems and answer their questions. Sometimes, participants would go to the same professional at both the public and the private health sector and would say that the approach of this professional in the two sectors was very different.

When you go to a private consultation, it could be the same professor who would have seen you [at hospital and], you can see the difference. You would say "is this the same person?" [At hospital] they are inundated with work [...] but you need to at least feel satisfied [with the visit]. […] Why should it be that I feel more satisfied when I pay for the

visit? And I feel better because I would have been *able* to talk. And even if I had questions, I would ask them, I would not mind because I know that the doctor would answer me. (Anne, 50Int)

Opting for both public and private care meant that patients were still prone to receiving conflicting advice. In these situations, the problem got more complicated, since participants were sometimes reluctant to tell doctors that they were seeking advice elsewhere. Thus, they would find themselves caught up between doctors' disputes and felt baffled, yet helpless about it. A female participant described her complicated situation when the doctor whom she visited at the public sector reduced the treatment prescribed previously by her private doctor.

> [on reviewing the treatment I was having], the doctor at the health centre shouted at me […] "You are going to destroy your liver, your kidneys, and you are going to destroy this and that!"[…] and he drove me crazy. [...] He even went so far as to say that whoever ordered this dose must be an ignorant specialist. [...] And he reduced two tablets and I reduced them immediately [...] and I am telling you, I became a wreck! My blood sugar shot up to such an extent that I was afraid to eat. [...] I lost a lot of weight, I lost many kilos and then I went to my private doctor and got told off from his side because he said "No one told you to reduce your medication" (Charlene, 60FG)

Issues of concern amongst participants regarding follow-up care which they received at the public health sector are represented in Figure 8.2.
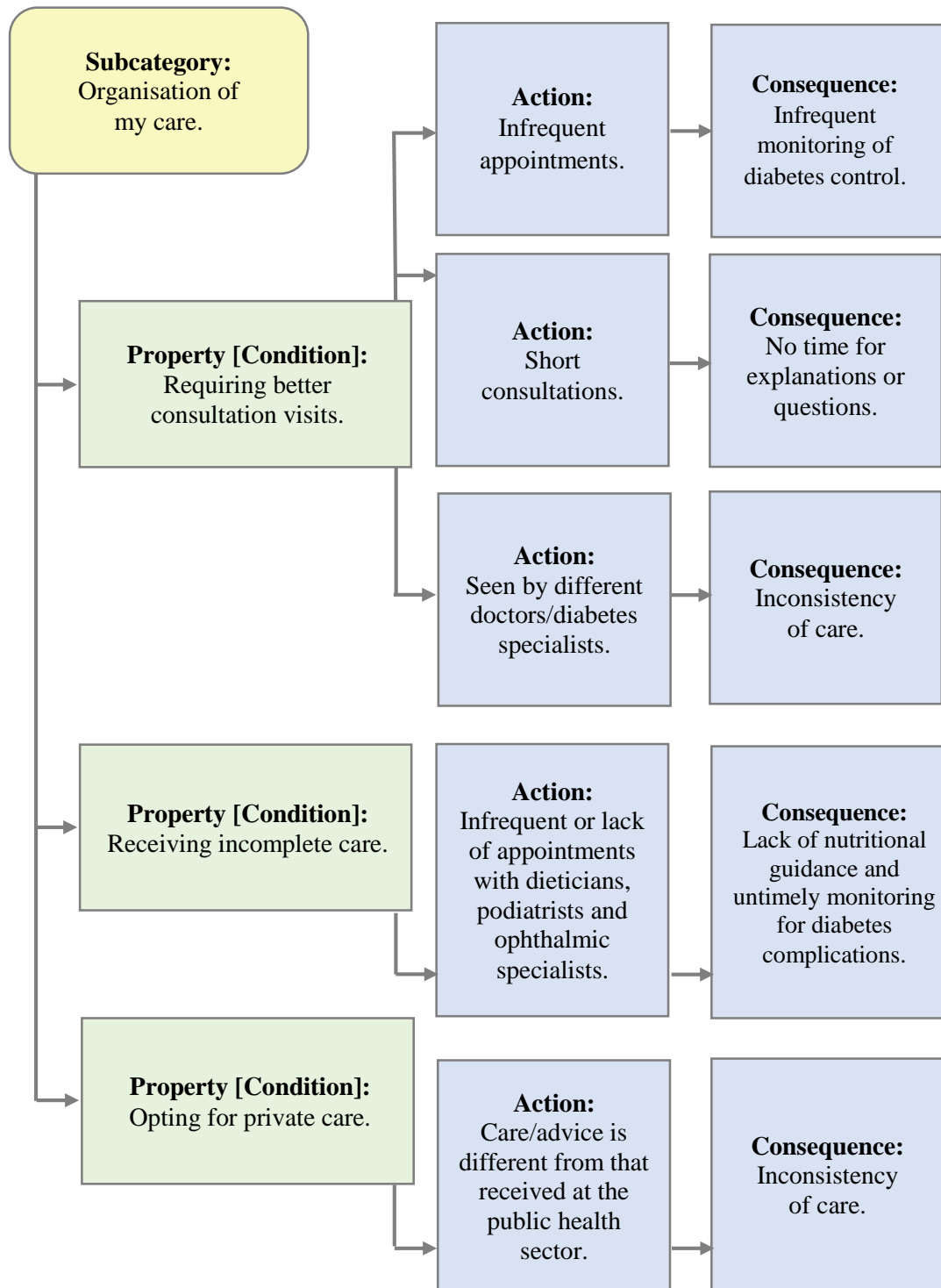
Figure 8.2   Issues of concern regarding diabetes follow-up care

8.3 Subcategory: My relationship with health professionals

This subcategory is about the relationship that developed between health professionals and patients during follow-up visits. Whilst these visits were viewed as the cornerstone of diabetes management, the relationship which is built between its two protagonists was seen to make or break their outcome. Participants noted how this relationship was shaped by the kind of communication which took place during their visits.

The properties of this subcategory represent two approaches to communication used by health professionals, which were seen to affect the patient-provider relationship in opposing ways. Communication could be insensitive and hinder the development of patient-provider relationship (such as that represented in the first property) or it could be helpful to relationship building and to supporting self-management (such as that represented in the second property). Participants generally talked about their relationships with doctors and most of this section will address communications occurring during consultation visits with these health professionals.

8.3.1 Property: Having insensitive health professionals

Participants construed insensitive care provided by some health professionals as being characterised by approaches to communication which reflected a lack of understanding of patients' situations and an authoritative and judgemental attitude. This is explained below.

The first step towards helping others is to understand their problem, however participants felt that some health professionals were not perceptive of their situation and failed to be empathic. As one participant put it, professionals 'could not put themselves in their patients' shoes.' This was seen as the reason why sometimes professionals gave unrealistic tips and set unattainable goals. Sometimes, health professionals were reported to give impractical advice as they ignored the context in which self-management occurred. They would give recommendations without considering what was going on in the life of the individual or with little regard towards the impact which their advice could have on the life of the person. For

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example, a male in his forties spoke of being advised by his doctor, to simply quit his job when he said that he was feeling stressed at work. Referring to this as 'easier said than done,' this participant considered the recommended solution to be over-simplistic and impractical. Another male participant described his experience of visiting the nutritionist who, he felt, gave him advice without considering his lifestyle and his previous eating habits. In the excerpt below, this participant recounts their conversation, adding a touch of humour and using the English language to refer to what the nutritionist said (hence her words are in italics). In Malta, the use of English language in everyday conversation is more common amongst those in the higher social class. Hence, this served to highlight the participant's perceived gap in social status between the nutritionist and himself. Also, the participant used humour to reflect how, in his opinion and due to his lifestyle, the nutritionist's advice was ridiculously impossible.

> [The nutritionist said] *"Two spoonful of oats in the morning"…* Now how can I have two spoonful of oats when I am used to having four slices of toast! […] *"At 10, eat an apple."* Now I work on scaffoldings, plastering walls all day, always on the go, I would be absolutely drained … ! *"Then at 12 o'clock [have] chicken."* I responded "Chicken? I guess you mean chicken kebab?!" *"No chicken kebab! And when you go home for lunch please have some vegetables and some …'* I left and never returned, because I said to myself, this is impossible! (Vince, 40FG)

Health professionals also communicated a lack of understanding of patients' needs when they used an inflexible approach in their recommendations. They would suggest a strategy, without considering other alternative approaches preferred by, or more familiar to participants. This rendered adhering to recommendations more challenging. A male participant whose nurse at the health centre insisted that he eats a specific type of cereal for breakfast, described this phenomenon by giving the following example.

> This is a condition which affects your life. It is like when you are used to doing something and then someone tells you [for example] 'Do not use this door". [You would say] "But I am used to using this door" He would say, "But you need to go round the block and get in through the other

door!" You will find this very disturbing. You would think, "Why should I not use this door if I can do so?" (Matthew, 40FG)

Other participants found it very difficult to follow extreme advice given by health professionals.

> [The doctor] told me "Eating sweets should not even cross your mind" because I told him that sometimes I have [sweets]. He said, "Not even sometimes, you should never even think about them." This makes you feel really sad. (Charlene, 60FG)

The experiences presented above were viewed as reflecting professionals' insensitivity towards challenges which participants had to face when self-managing their diabetes. Participants also felt that their health professionals were insensitive when they communicated with their patients in an offensive manner. For example, some participants conveyed being shouted at or reprimanded by their doctor when their blood sugar levels rose or when they reported non-adherent behaviour. They felt as though they were being judged when this happened and were exasperated by this behaviour. A female participant spoke of how her doctor would tell her off when she would not commit herself the way he expected her to.

> [The doctor] would tell me, "Today [your blood sugar] is a little high." I would tell him, "Yes, do you know why? Because yesterday" or for example, "A couple of days ago, [I ate …]" [he would say,] "Then what did you come here for, to waste my time!?" (using a high tone of voice) (Sue, 60Int)

Another example was given by a young male participant who described the manner by which a doctor gave him news of his diagnosis. The doctor used a reprimanding approach, seasoned with a pinch of sarcasm. Anger towards this doctor still radiated from the participant, years after his diagnoses, as he recounted the incident.

> In the beginning, when I had just been diagnosed, I visited a doctor at the health centre, he saw my blood result and said, "Well done you clever so and so!" I said "What is this all about?" He said, "Go to the hospital now and start getting injected!" That is how he said it! I said, "But what do you mean?" He told me, "Here." My blood glucose result was high, about 14. He said, "You have diabetes!" He told me, "Now, go to

hospital so that they can start injecting you!" Just like that, I felt like ...
(Stephen, 30Int)

Besides anger, offensive communication elicited other emotional reactions, such as feeling patronised, overpowered and insignificant. One participant felt like being brought down to "zero." Participants again interpreted the reprimanding approach used by health professionals as being treated like children and they would react accordingly. Some reported acting rebelliously by disregarding recommendations or doing the opposite of what had been suggested. Becoming vindictive with food immediately after the consultation was conveyed by a young female participant.

> After being shouted at, at the Diabetes Clinic, I go to the canteen and stuff my face. Just like that! Because I feel very angry. I would say "Here I am, she is shouting at me and ordering me around!" [...] I hate it when they treat me like a child. (Sandra, 18Int)

Overall, this approach to communication instigated negative reactions and was reported to demotivate participants. The following excerpt illustrates one exception.

> When you talk to my doctor, you would find he is the strangest man on earth, but I got used to [his shouting]. I am no longer bothered about it [because] when you have a problem he changes completely. He sits with you, he explains things, he shouts at you only when needed. (Alfred, 40FG)

The idea of 'needing' or 'deserving' a scolding, as indicated by Alfred in this excerpt, was mentioned by another female participant. She felt that sometimes doctors needed to act this way especially when patients relinquished their responsibility towards self-management.

Doctors were also perceived to be offensive when they used fear tactics to motivate participants to change their behaviour. Doctors would threaten to increase their treatment, start them on insulin or would try to shake them out of their 'indifference' with the thought of amputations. Participants loathed this approach. They interpreted this as being threatened by punishments for their wrong doings. Finally, participants also showed disapproval of some health professionals' non-verbal communication. A few of them reported not being looked at during the consultation.

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Doctors were completely absorbed with reading their results and writing their prescriptions. This projected a strong feeling of not being cared for, of having a doctor who looked into their diabetes *through* them but not *with* them.

> [the doctor] writes, he writes all the time and that is it. Last Thursday [during my visit] he almost never lifted his face from the paper. I don't even know what he looked like. (Janet, 70Int)

8.3.2 Property: Having helpful health professionals

Whilst most of the talk about health professionals was negative, a few participants had considerable praise for health professionals who were perceived as sensitive to their needs. Some would be professionals they had come across in the public health sector. Overall, the message was that you find 'good' and 'bad' professionals everywhere, both in the public and private health sector. Again, most of the conversation about helpful professionals was about doctors and this is what will be presented in this section.

Participants were very appreciative of doctors who treated them in a 'friendly' manner, as their equals, as adults, using a non-authoritative approach. This was when doctors listened to them, gave them time to talk and ask questions, gave them information, discussed treatment options and responded to their problems in a non-judgemental way.

> The way the doctor spoke to me was not *patronising,* like "I am telling you this and make sure you do this!" He had a way of getting a message across. Even when he found that I had a problem [with glucose control], the way he responded to it did not make me rebel against him. [...] He said, "Look, you have a problem [with your blood glucose], *it's up to you, up to nobody else.* It's in your hands, you are not a child. You know what the problem is and you know what the repercussions are." He talked to me like I was his equal. (Daniel, 40Int)

Giving realistic goals or reasonable recommendations was considered to make adherence much easier. For example, a male participant who had been obese told how his doctor staged his goals for weight reduction, so that he would not give up. Being positive and praising success was perceived as yet another highly effective

approach. For a male participant, this had been the turning point in his diabetes management.

> Since [my doctor] told me that I was doing well, I got encouraged. I had been managing very badly. [...] That is what I need, a little help. [Last time] he told me, "Well done, you have lost some weight again." That is what I need to keep moving forward. (Frankie, 18Int)

As mentioned above, participants viewed a positive approach as being a reflection of genuine interest in their well-being. As a result, they felt more motivated, they trusted their doctor and felt safer under his/her care. They also felt treated like a person rather than a number. Sometimes, they referred to such care as 'excellent' and an elderly male participant even compared his doctor to a saint. Frankie, the participant who talked about how positive and supportive his doctor had been, (see excerpt above) referred to the difference which this doctor made in his life compared to the previous 'insensitive' doctor who he used to visit in a private clinic.

> One doctor would see you are doing badly, *uppp uppp* [he starts writing] … he increases your medication and leaves, with a sort of, 'Let's get it over and done with' attitude. This one takes interest, a lot of interest and he reduced my tablets. The [new] doctor has made a difference to me, a huge, huge difference! (Frankie, 18Int)

The importance attributed to sensitive communication from health professionals was repeatedly reflected in how participants answered to questions related to their views about good quality care.

> What's the use of having a *centre of excellence?* (term often used to describe the new general hospital) ... It is the *knowledge*, the *know-how,* the *interaction,* the communication between doctors and patients … all these things [that are important]. We could have a [diabetes] centre as big as the whole hospital … but unless they emphasise *on the human element,* it will be of no value. (Daniel, 40Int)

Figure 8.3 compares accounts of participants' experiences of having helpful and unhelpful health professionals.
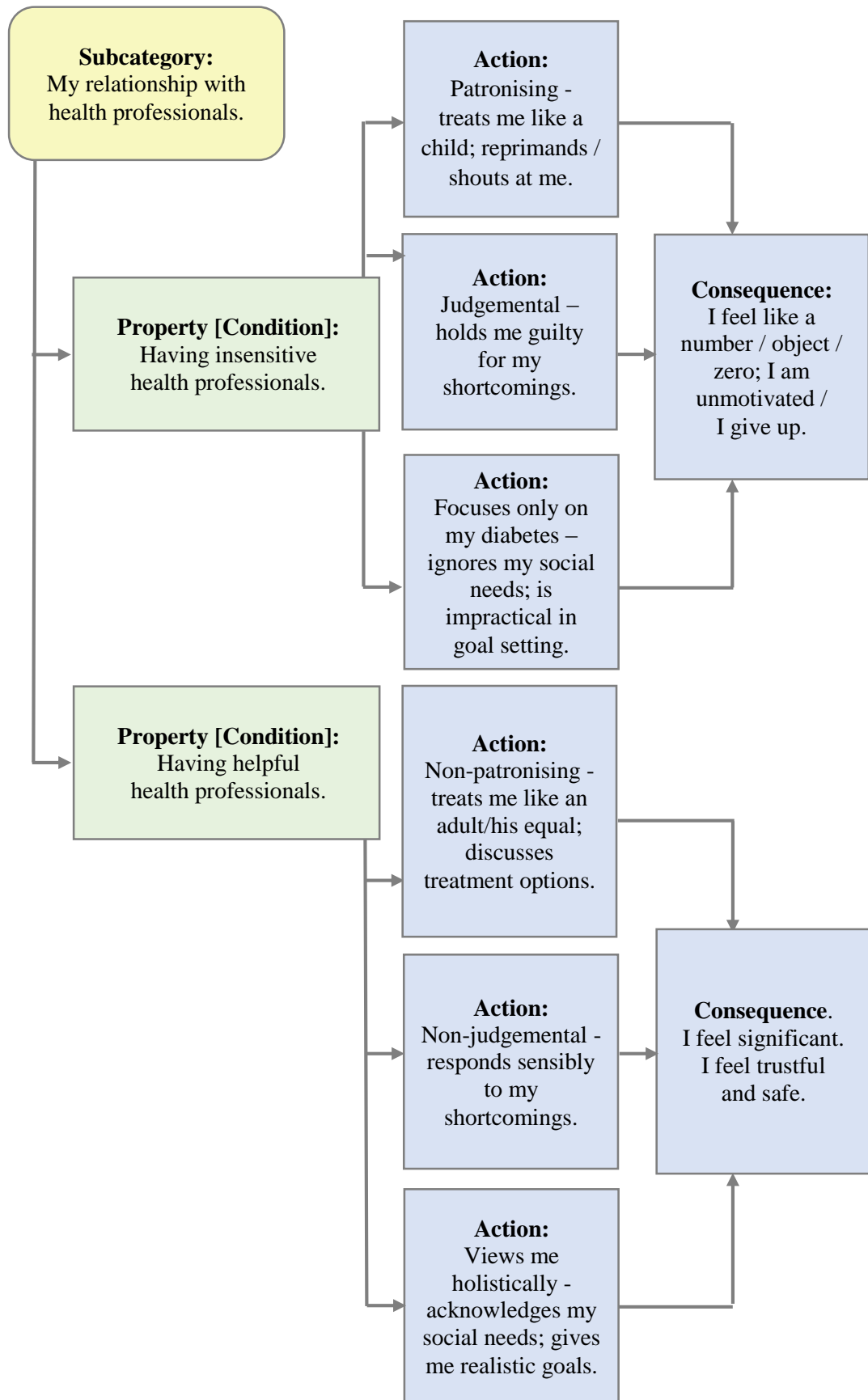
Figure 8.3   Participants' experiences with helpful/unhelpful health professionals

8.4 Subcategory: Having access to resources

This subcategory is about resources which participants needed in order to carry out daily self-management activities. These included the actual 'tools' for practice, such as self-testing equipment, as well as information about self-management. The properties of this subcategory represent two areas of concern surrounding this subject area, namely the financial demands of having to buy resources for self-management and participants' access to information.

8.4.1 Property: Coping financially

Participants knew they were being interviewed about their needs for self-management support and came prepared to talk about the financial support they expected from government, about which they were generally dissatisfied. Participants spoke mostly about test strips required for checking blood glucose. They expected to get them for free, considering the expense involved with regular monitoring. Some would not check their blood glucose daily because of this issue. Others complained of being given only ten syringes for insulin per month, when they needed to inject themselves once or twice daily.

> I take insulin. You go to get a prescription and they give you twenty [syringes] to inject yourself with, for a whole two months, when on the package, you have written that you have to use them once. (Emman, 50FG)

A male elderly participant used his disposable syringe four times in a row because of this problem. Yet other participants complained of having to buy their own medications because the ones they were having were not part of the list of medications covered in the national scheme for free medications. Another financial issue which arose was the expense involved with buying health food, such as fresh fish, whole wheat pasta or food produced specifically for diabetes, such as sugar free chocolates or biscuits.

8.4.2   Property: Having access to information

Participants' general opinion was that their access to information was poor, although a few participants were satisfied with the information they received, particularly from the media. Most of the discussion was about information given (or not given) by health professionals during follow-up visits. Besides addressing participants' views about this information, this section will present findings about preferred and actual sources of information and diabetes education programmes.

Some participants were satisfied with the information they received about their diabetes from their doctors or nurses. A few participants had the opportunity to meet up with a nurse specialist (only patients with particular educational needs are referred to nurse specialists) and they spoke highly of the information given and so did most (although not all) of the participants who received advice from nurses working at health centres. On the other hand, participants did not report receiving any information/advice from nurses working in the hospital clinic. In fact, most of the participants who brought up the issue of information expected more of this during follow-up visits.

Participants wanted more information about treatment decisions and more explanations of management issues, such as dietary management. But what seemed to irritate participants most was the lack of information regarding their test results. The doctor's statement, 'All is well with your results' fell short from satisfying most participants who expected to know exactly which tests were taken and what their result was, particularly for their glucose and cholesterol levels. Participants felt deprived of their rights when this information was withheld. One participant saw this as an insult to her intelligence as she felt that her doctor underestimated her ability to comprehend the information.

> [The doctor] would not tell you what the blood results are, what the levels are and that is something which irritates me. They, sort of, treat everyone as ignorant or not able to understand and I would want to know what the level is. (Anne, 50Int)

Although participants spoke about having poor access to information, as though information was an important resource, there was little discussion about their information seeking behaviour. In general, it seemed as though they were quite passive about this issue. Participants were asked how they preferred to obtain information and how they actually got the information they had. Leaflets were the information source most preferred by participants. They expected to get practical information from this source, such as dietary plans, recipes and practical tips. A couple of participants also suggested a helpline as a way of ensuring timely information.

Despite preference for leaflets as a source of information, only a very few participants spoke of having got their information this way. Participants were not given leaflets by health professionals unless they asked for them, themselves. The source of information most commonly accessed was the internet, although again, only a few participants used this and these were mostly the young or educated participants. A common problem expressed by internet users was finding reliable websites. They would find countless sites of information but knew little of which sites to trust. There was no evidence of health professionals giving patients websites from where to access reliable information.

Another source of information discussed was diabetes education programmes. These are organised at the general hospital and attendance is by invitation and free of charge. Educational sessions are also organised regularly by the Maltese Diabetes Association. It was important to note that these classes were never brought up by participants during discussions. The data gathered about these sessions was obtained by my asking questions about the subject.

Only a small number of participants reported having attended educational classes and most of them had discontinued their attendance, mostly for practical reasons, such as having to travel. In fact, only a small minority of participants said that they had been invited to attend an educational programme. When I asked about this during the focus groups, there were times when no-one from the group mentioned that they had been invited, some did not even know about the availability of this educational opportunity. Opinions about the importance of educational programmes

were varied. Some felt that they would be useful, especially since the classes would give them the opportunity to meet others living with this condition. Others felt that classes were likely to be a waste of time, even possibly boring. They felt that they would only receive impractical advice or simply hear a repetition of the same information that they already knew about. In fact, some of them stated that they would not attend at this stage, even if they were invited to attend since they had become set in their ways in which they handled their condition and already knew enough about it.

> They have never invited me [for the education programme]. Probably since I have had the condition for such a long time, over the years I have got the information I need, sort of. (Sandra, 18Int) (This participant had diabetes for seven years.)

Participants were asked to give their opinions of how to organise such programmes. The most common suggestion was that they should be organised in small groups and based on group discussions where individuals would be able to participate and learn from others' experiences. Figure 8.4 summarises issues brought up with regards to resource provision.
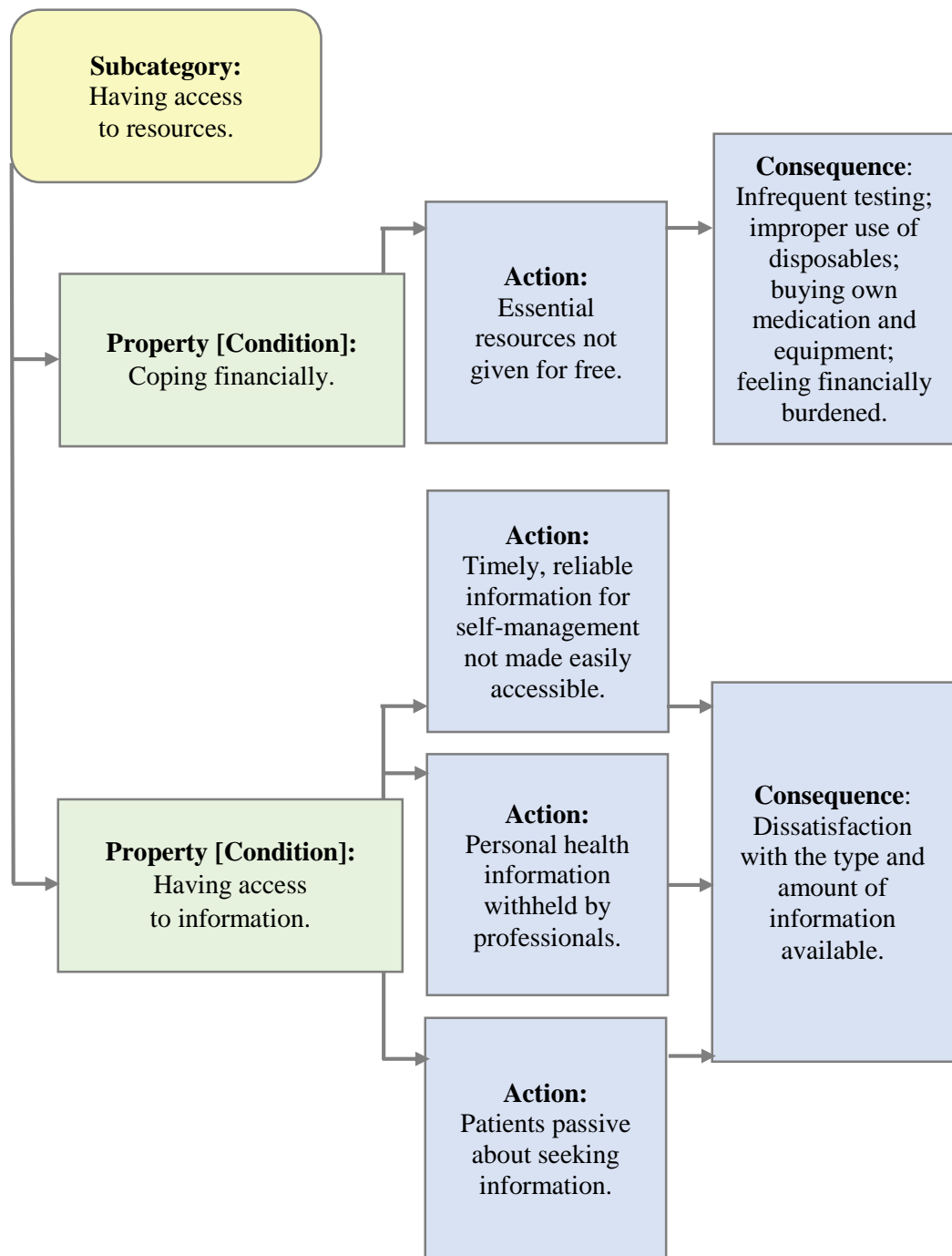
Figure 8.4   Issues regarding provision of resources for self-management

8.5   Summary of findings

The follow-up visit was construed as being central to effectively support diabetes self-management, but for many, the all-important consultations with health professionals did little to guide their efforts or motivate them to better manage their condition.   The way that follow-up care was organised seemed to fall short of providing timely monitoring of diabetes, continuity of care, opportunity to discuss management concerns and a comprehensive package of care.   Because of this, a number of individuals opted for private care which could still not iron out problems, due to, for example, inconsistency in care.

Besides shortcomings in care organisation, health professionals were perceived as being insensitive when they talked down to their patients, became offensive and expected patients to comply unquestioningly.   This, coupled with health professionals' inflexible approach and inability to look beyond their patients' diabetes, rendered care impersonal, recommendations impractical and professionals' attitudes judgemental.   But the situation was not consistently negative.   Within the same organisational settings, some professionals still managed to give time to patients and instil a sense of care, respect and understanding which motivated and supported patients in their self-management.   These professionals were seen to make a great difference to helping patients in their diabetes self-management.

Participants talked of needing resources for everyday management.   A common expectation was that resources should be provided free of charge.   Participants also viewed information as an important resource but active information-seeking behaviour seemed to be lacking.   Doctors had little time to educate their patients, whilst participants often reported not being referred to dieticians or nurse educators and not being invited to education classes.   Patients were left to turn to printed or electronic information for education.   However, although participants construed this as a good mode of education, they seemed hesitant to actively access it.

Part 2: Discussion of findings

8.6   Introduction

Issues regarding access to healthcare were often brought up during interviews. In fact, I noticed that participants actually came to the interviews *prepared* to voice their concerns about this subject area. This could mean that individuals who were dissatisfied with the care they had received saw participation in this study as a unique opportunity to voice their disapproval. This may have acted as an incentive to participate. Thus, dissatisfied individuals may have been more likely to accept to participate and this could possibly explain why most discussion about health services was generally negative. In view of this, every effort has been made to compare findings of this study with information on Maltese diabetes services obtained from other sources so as to determine whether the literature contradicts or supports participants' accounts. Foreign literature on views about diabetes services will also be used in this section. Before proceeding to discuss findings presented in this chapter, the following section will give an overview of the Maltese healthcare system and diabetes health services, adding to information presented in Section 2.5.3.

8.7   The healthcare system in Malta

Information about the Maltese health system, which is presented in this section, has been obtained from a Maltese publication (Azzopardi Muscat *et al.,* 2014), which forms part of the Health System in Transition series (HiT) compiled by the European Observatory on Health Systems and Policies.

In Malta, the Ministry of Health is responsible for the provision of health services while Parliament is responsible for approving the healthcare budget and enacting healthcare legislation. In the public healthcare system, decisions regarding governance, regulation, provision and financing of services are highly centralised. Also, consumers are not generally represented in decision-making bodies in healthcare. The public healthcare system is the main provider of health services,

incorporating universal coverage. Preventive, curative and rehabilitative healthcare is provided free of charge to all local residents. This can be accessed at community and hospital-based settings.

Health services are also provided by the private sector, approximately a third of the health expenditure is through private spending. As a percent of GDP, private spending is high compared to the EU average. Private care is mainly community-based, in fact, two thirds of the Maltese opt to use private GP services. This is likely due to the fact that in the public primary health sector, there is currently no system of patient registration with doctors or group practices. Patients are seen at health centres by the doctor on call, thereby hindering continuity of care. In the private sector, patients have direct access not only to GPs but also to specialists (that is, using self-referral to doctors/specialists of their choice).

Medicines listed on the Government Formulary List (GFL) are provided free of charge to patients who qualify from means testing and those with particular chronic illnesses, one of which is diabetes. The latter group are only entitled to drugs related to their chronic condition/s and to only those included in the GFL. Individuals not falling under one of these groups have to buy all their medications.

The public system is funded by general tax revenues, while the main private sources of health financing are out-of-pocket (or direct) payments. This comprises 94% of private healthcare expenditure, which is also high compared to other EU countries. Most of the private expenditure is spent on GP services and specialist outpatient care.

Health services are run by a lower concentration of health professionals than the EU average. Professionals are generally paid with a salary, however a significant number of doctors and paramedical salaried professionals in the public health sector also have a private practice which is paid on a fee-for-service basis.

In the public health sector, there is generally a lack of an organised and comprehensive system for monitoring quality of care and healthcare outcomes. As in other countries, sustainability remains the major challenge for the Maltese

healthcare system, as it faces rising costs of medicines and technology, as well as increasing demands from its ageing population.

8.7.1　　Diabetes-related services in Malta

Information related to diabetes services at the public health sector has mainly been gathered from interviews carried out with doctors and nurses working at the hospital and community-based clinics who have administrative and clinical roles. This is discussed in more detail later on in this chapter when discussing related findings.

As with other chronic illnesses, diabetes-related services and pharmacological treatment are provided by the public health system free of charge, regardless of one's financial means. However, as mentioned above, diabetes drugs not represented on the GFL have to be bought by patients for whom these are prescribed. Diabetes follow-up care is also provided at the private sector by GPs and medical diabetes specialists and it is up to the patient to choose between private and public healthcare.

Follow-up care in the public sector takes place either at the Diabetes and Endocrinology Unit which is situated at the Outpatients Department in Mater Dei Hospital, or at diabetes clinics in community-based health centres. Patients with Type 1 diabetes and those with Type 2 diabetes who are not well controlled are seen at the hospital clinic by medical diabetes specialists. Those with Type 2 diabetes who are well controlled and without serious complications are followed up at health centres and seen by GPs who may have a special interest and some training in diabetes care. In neither type of clinic are patients followed by the same doctor or specialist, except for those health centre clinics where there is a doctor with specialised training in diabetes care. A shared care programme is in place between community diabetes clinics and the hospital clinic whereby patients are referred to and from the different clinics, as needed. There is currently no ICT system in place to record patient care in any healthcare department and this tends to compromise the integration of care given by different members of the healthcare team and at different settings. During each follow-up visit, full blood investigations are taken, including lipids, kidney function and HbA1c.   Screening facilities for eye and foot

complications are available at both hospital and community-based clinics. The plan is for patients to receive yearly screening at these clinics.

The main role of general nurses in diabetes clinics during follow-up care consists of monitoring blood pressure and blood glucose, urine testing and measuring weight. However, some nurses working at health centre clinics reported also giving patients self-management advice during their follow-up appointment, as the need arose. Whilst there are approximately 40,000 Maltese individuals with diabetes, there are currently only two diabetes specialist nurses in Malta, who have received specialist training, and they are stationed at the hospital clinic. Their role, shared with another nurse with no specific training in diabetes, mainly consists of staff training and providing education to all individuals with Type 1 diabetes, gestational diabetes and those with Type 2 diabetes when they are prescribed insulin. Currently, nurses working at the diabetes clinics in health centres are being given the opportunity to receive further education in diabetes management, but they have not as yet been appointed as diabetes nurse specialists. Also for some of these nurses, their role extends beyond the diabetes clinic, to other areas of the health centre, unrelated to diabetes care. There are currently plans for this situation to change.

There is a National Diabetes Association which is a non-governmental, non-profit voluntary organisation providing support and education for Maltese individuals with diabetes at a minimal annual membership fee. There is currently no national screening programme for diabetes and no diabetes register. This makes it difficult to monitor service provision and service outcomes. A first ever national diabetes strategy was developed and published in December 2015 for the period 2016 - 2020 (Ministry of Energy and Health, 2015).

The following sections will discuss participants' views about the quality of care they received. These views have been grouped into three main pillars of care: organisation of care, relationship developed with health professionals as well as access to resources for self-management.

8.8 Organisation of care

Participants construed follow-up consultation visits as being centrally important to their diabetes management. It was clear that satisfaction with care was often dependent on issues surrounding this visit, such as how often it happened, how long it took, and the continuity of care it provided. These factors, together with other issues determining comprehensiveness of general diabetes care, will be discussed in this section.

The most frequent health service complaint was about the long intervals between follow-up appointments, particularly at the hospital clinic, where these extended from twelve to eighteen months. This issue was discussed with a health professional working in diabetes care, who confirmed that the long intervals were a common occurrence and who gave me information related to this shortcoming in service provision (Grixti, personal communication, June 2015). Within this long interval, patients are not generally reviewed by doctors or nurses in the public health sector, except in special cases, for example when a patient has recently been prescribed insulin. These cases are seen by the specialist nurse who reviews their self-care. This practice is not in line with the IDF guidelines, which suggest that patients with Type 2 diabetes should have at least one comprehensive yearly review with scheduled routine visits in between (IDF, 2012). Infrequent appointments were the main reason why participants opted for private care in between hospital appointments and many visited their private GP. An important issue here is that there is no system of communication between these GPs and the medical specialists at the hospital which, as has been shown in this study, does at times cause problems.

This shortcoming is very likely due to the lack of diabetes medical specialists at the hospital clinic, who are the ones who review patients at this clinic. This shortage could be addressed by further recruitment and training of medical specialists. However, one may also examine whether patients seen at the hospital clinic really need to be reviewed by a medical specialist at every appointment. As suggested by Grixti during our interview, one could consider reviewing the system of referral of patients from health centres, to see whether less patients actually need to be referred to the hospital clinic to be reviewed by medical specialists. Also, an in-depth

assessment would very likely reveal that qualified diabetes nurse specialists, could effectively review patients at the hospital clinic, in between medical specialists' appointments. These would have direct access to medical specialists with whom they could discuss patients, if and when needed. The role of nurse specialist in follow-up diabetes care will be discussed below.

As stated by Vrijhoef *et al.* (2002), a possible solution to the problem of increased prevalence of diabetes which is resulting in heavy workloads on physicians is vertical substitution of care. Here, professionals at different levels of expertise (such as doctors and nurses) share tasks and responsibilities to bridge deficiencies in care. In various countries around the world, the role of nurses has developed in such a way that their specialist skills have entered areas which were traditionally seen as forming part of the doctors' role. This shift of responsibility to specialised nurses has occurred in a number of health specialities. This section will focus on this shift within the area of diabetes.

Studies investigating the role of nurse specialists as central carers in diabetes management have shown this to contribute to positive outcomes (Vrijhoef *et al.,* 2002; Taylor *et al*., 2003; Ubink-Veltmaat *et al.,* 2005; Houweling *et al.,* 2009). Most of these studies either lacked a randomised controlled trial design, or were controlled trials with a small sample size, indicating the need of more work in this area of diabetes care. Arts *et al.* (2012) who evaluated cost-effectiveness of substituting physicians with diabetes nurse specialists as main care providers, have found nurse specialists to generate reduction in costs as did the controlled trial conducted by Houweling *et al.* (2009). Qualitative research conducted in this area found nurse-led care to promote relationships based on openness and collaboration and this led to patients feeling more informed, listened to, and ultimately more confident and independent in self-management (Edwall *et al.*, 2008). In fact, increased patient satisfaction has been a key finding in research conducted in this area of diabetes care (Houweling *et al.,* 2009).

The evidence available to date may point to advantages with expanding the role of nurse-specialists in diabetes care in Malta, in order to overcome the shortage of physicians and the resultant infrequent follow-up appointments. However, the

success of such initiatives is likely to be influenced by cultural issues which may, for example, determine the effectiveness of team work between health professionals. An ethnographic study conducted by Formosa (2009) has provided valuable evidence around this subject area. This study was aimed at exploring the culture behind the provision of diabetes-related services in Malta and because of its relevance to this study, it will be referred to repeatedly in this chapter. Formosa conducted formal interviews amongst five health professionals, one of whom was also a service user. Participant observation at the hospital diabetes clinic was also carried out. Reflexivity was used throughout the study and this was an important strength of this work. However, little is written on how observations were conducted and the data they produced.

From the interviews conducted, Formosa (2009) found significant authority and power relations between health professionals, which acted as barriers to diabetes care. For example, decisions on healthcare were found to be taken only by professionals at higher authority with little or no consultation with those with more clinical experience. Power relations between nurses and doctors have been documented in other studies carried out in Malta. For example, a study by Petrova and Camilleri (2015, p. 45) amongst Maltese practice development nurses found that, when trying to introduce new practices, these nurses experienced barriers due to resistance from consultants who were said to 'dominate' them. Trapani (2014) conducted a Grounded Theory study to explore how Maltese nurses working in intensive care sought help from medical practitioners when making clinical decisions. Trapani (2014) found that despite their desire to act with some degree of independence, nurses had to be constantly mindful of their unequal decision-making power in relation to doctors and this affected the way in which they made clinical decisions. These factors may also prove problematic when trying to expand nurses' roles in care. In fact, despite the increasing number of nurse specialists in different areas of care in the local health system, they are generally not given the right to take decisions upon treatment or even the right to order routine investigations. There seems to be pressure for these tasks to remain the sole responsibility of the medical practitioner. Whilst this situation persists, nurse specialists' role in follow-up care will remain limited. Further studies of cultural issues surrounding this service development may help to establish how the role of nurse specialists in Malta could

improve diabetes services, while enhancing financial sustainability. Such studies should also address patients' perceptions of being shifted from doctor-led to nurse-led care.

Another factor which participants of this present study were concerned about was the short duration of their follow-up consultation visit. Because time is crucial for the exchange of information and relationship building, participants viewed this shortcoming as allowing no time for discussion and rendering the visits highly impersonal. Participants said that the main activity taking place during consultation visits was the doctor's review of blood test results and of the treatment plan. This poorly compares with IDF (2012) recommendations which stipulate that during the annual review, besides reviewing medication, health professionals should assess self-care knowledge and beliefs, lifestyle adaptations and wishes, psychological status and self-monitoring activity. Some participants developed the impression that doctors had little time for them, particularly with those doctors who discouraged questioning. The result was that they became "afraid" to ask questions. On the other hand, other participants commented that their doctors dedicated enough time to them and listened attentively to their questions. Thus, whether hurried consultations were a result of the circumstances under which the consultations occurred or due to the attitude of the individual professional remains unclear.

This consultation-related experience does not seem to be unique to the Maltese situation, as various foreign studies reported having participants complain of short follow-up visits (e.g. Lawton *et al.,* 2005; Shakibazadeh *et al.*, 2011). Quantitative studies have also highlighted patients' preference for longer consultations. For example, Grol *et al.,* (1999) who studied individuals' preferences for GP diabetes care across seven different countries, found that, amongst participating countries, the highest priority in general was having sufficient time during consultations.

Although, as mentioned above, considerations shed doubt on whether short consultations were really a result of issues related to limited time, participants in this study did seem to be preoccupied with the problem of time shortage. Sometimes, they blamed this on the fact that consultations at the public health sector were free of charge and that therefore they could not expect any better. Their perceptions about

time limitations clearly changed when they opted for private consultations. Here, they felt they had the right to ask questions as they were actually 'buying' the time. The option available for private consultations thus seemed to lower individuals' expectations of the consultation held at the public health sector, the general idea being that discussion of treatment is beyond basic care and had to be paid for.

The arguments presented in this section seem to indicate that the use of time in a consultation may be determined by issues related to attitudes, and the setting in which the consultation takes place. These findings are related to the nature of the health system in Malta and attitudinal factors shaped by Maltese culture, which will be discussed later on in this chapter.

Participants also complained of a lack of continuity of the healthcare provider, since they were seen by different doctors/specialists during follow-up visits. According to participants, this did not give their providers the opportunity to get to know them well and it also resulted in inconsistent care, whereby opinions related to management varied amongst professionals. These factors caused confusion and lack of trust amongst participants regarding the care they were receiving. Three factors in the local scenario are likely to exacerbate these problems, namely the lack of electronic patient records which facilitate sharing of information between health professionals; the lack of clinical guidelines for diabetes management which standardise care and the unprofessional behaviour amongst doctors who at times, not only openly disagree with treatment decisions of other specialists, but also undermine these decisions.

Haggerty *et al.* (2003) refer to three types of continuity of care, namely relational continuity characterised by an ongoing relationship between patient and provider, management continuity characterised by a consistent approach to management and informational continuity whereby information shared with patients remains consistent. The comments by participants of this study illustrated how being seen by different health professionals jeopardised these three aspects of continuity.

The participants also lamented about receiving incomplete care. They reported receiving no/infrequent screening and poor nutritional guidance. Foot and eye

screening did not occur on a yearly basis, as recommended by the IDF (2012). These findings are supported by those obtained by Montebello (2014) who carried out an audit of diabetes care in the Maltese primary healthcare sector, and found that over a period of twelve months, only 71% of patients had their eyes screened and 59% had a podiatry appointment (cited in Ministry of Energy and Health, 2014, p. 17). An outcome measure of foot screening is the incidence of lower leg ulcer/gangrene. These have been reported to increase from 192 in 2010 to 322 in 2013 (Ministry of Energy and Health, 2014b). The new national diabetes strategy has addressed this problem, proposing regular screening which will be enhanced by establishing a formal screening protocol, whereby individuals will be invited for screening at pre-established intervals (Ministry of Energy and Health, 2015).

The lack of nutritional guidance reported by participants is worrisome considering the central role of nutritional management in glucose control. For many of the participants, nutritional guidance was not received from doctors, nurses or dieticians. Participants were left to work out their dietary management on their own. This lack of nutritional service is a direct result of the lack of personnel available to offer this service. Three full-time and one part-time dietician are employed to cater for all medical cases that require dietetic interventions in the public health sector (Ministry of Energy and Health, 2014b). In fact, in Malta there is currently no dietician dedicated to the care of diabetes patients only. This issue has also been addressed in the new National Diabetes Strategy and new training schemes have been initiated to increase the number of individuals specialised in this field.

While participants discussed various aspects of follow-up care, as mentioned in the sections above, the main focus of the interviews was the doctor-patient relationship which developed during follow-up visits. This will be discussed in the next section.

8.9   The patient-provider relationship

Participants frequently brought up their experiences of the patient-professional relationship during interviews. This seemed to dominate their overall experience of care and determine the extent to which they were satisfied with such care. Most of the discussion was about negative aspects of this relationship, but positive comments

also featured across the interviews. Literature about the therapeutic patient-professional relationship is vast and the related findings of this study have added little to that which is already known about this subject area. However, the nature of participants' *response* to these situations is particular to the Maltese scenario.

Participants generally complained when they perceived that their health professionals, particularly doctors, were being authoritative in their approach. They judged this through the way professionals communicated with them, through the way they avoided discussion of treatment and refrained from giving them the information they needed, thereby retaining the power to make management decisions. Health professionals were perceived as being insensitive when they were judgemental and gave impractical advice with no consideration to life situations which would influence their self-care. This kind of attitude was identified in Formosa's (2009) ethnographic work whereby health professionals whom she interviewed tended to blame Maltese patients for their poor levels of self-care and diabetes outcomes. Formosa (2009) continues to state that not all professionals welcomed concordance in their clinical practice and some were hesitant with giving priority to their patients' views.

Various studies about diabetes experience across different cultures have found participants to be somewhat dissatisfied with their patient-provider relationship. For example, Stiffler *et al.*'s meta-synthesis (2014) involving twenty one studies found that doctors were often reported to miss the emotional component in care, Vermeir's (2007) meta-ethnography incorporating seven studies conducted in different countries, found that doctors were viewed as being judgmental towards overweight patients who were blamed for their condition, Richards *et al.* (2006) found that participants resented unrealistic expectations from their health professionals while participants in studies carried out by Cooper *et al.* (2003) and Hornsten *et al.* (2005) disliked the authoritative approach of their health professionals. Furthermore, a review of diabetes-related studies (mostly qualitative) with South Asian participants, conducted by Sohal *et al.* (2015) found that although South Asians respected the expert knowledge amongst their professionals, they detested their lack of empathy towards the difficulties experienced in overcoming barriers to self-management. These qualitative studies varied in their methodological approaches but were all

based within diabetes care settings. Hence, despite the potential benefits of a therapeutic patient-provider relationship, various issues still seem to hinder this relationship from developing and these will be discussed next.

The Maltese and foreign research findings referred to above, have highlighted an important shortcoming in the patient-provider relationship: the lack of a holistic and collaborative management. The literature points to this shortcoming as stemming from the health professional's tendency to keep holding on to the traditional bio-medical model of health. Here, the focus is on disease and the resultant alteration in biological structure and function (Kleinman, 1988). This contrasts with the social model of health often held by individuals with chronic illness who need to integrate their illness into their social life. The focus here is on the illness experience which incorporates social and psychological aspects of such experience (Kleinman, 1988). Thus the goals for management between patient and provider become incongruent and collaboration fails. In this present study, this difference in perspectives of diabetes management was highlighted in participants' accounts of their consultation experiences.

As noted by Campbell *et al.* (2003) in their meta-ethnography of studies examining individuals' experiences of diabetes, when health professionals focus on the biophysical consequences of diagnosis and treatment, they fail to view patients within context. This was a common concern of participants of this study, who felt that doctors were unreasonable in their advice as they had little knowledge or regard to their social situations which made the application of this advice difficult or impossible. Kleinman (1988, p. 180) writes how by viewing patients out of context, "we place complex individuals in simple, unidimensional roles [such as diabetics] as if this were all they are and can be," and he continues to state that "to understand the contribution of the social environment to chronicity … we must be able to see the patient suspended, as it were, in the web of relationships that constitute a lifeworld." Learning about the impact of these relationships on patient care requires time and cannot happen when consultations are brief and focused solely on laboratory values, as was reported by participants of this present study. Spenceley and Williams (2006) also state that the tension between the doctor's disease-oriented approach to self-management and the patient's life-oriented approach may go unrecognised within the

dominant view of the doctor. However, when and if this tension surfaces (that is, when patients argue against doctors' recommendations), this is likely to be dismissed as non-compliance. This is related to the authoritarian attitude amongst health professionals which is explained next.

When care is based solely on medical consequences of disease the doctor, who has specialised knowledge on such a focus of care, becomes viewed as the person with power and authority to manage the disease. Mc Cullough (2009) writes that such intellectual authority has only been happening within the past century with the establishment of a reliable scientific basis for diagnostic and clinical procedures. However, Freidson (1972), who has written extensively about the authoritarian disposition amongst doctors, states that such disposition is not only attributed to the prestige gained amongst laymen because of the doctors' specialised knowledge, but also to the relations which doctors have traditionally developed with organised political power structures. Doctors' authority thus extends beyond the patient-provider relationship to include authority over major political decisions which influence the organisation of healthcare.

As stated by Freidson (1972), the authority assumed by the professional during consultations, is often translated into a right on the doctor's part to decide what happens to the patient, such as what treatment is to be given and how the patient is required to act during illness. This situation has been referred to by participants of this study who expressed disappointment towards the lack of discussion and the inflexible imposition of recommended management practices. Authoritarian attitudes also determined communication styles used by health professionals, which were perceived as offensive, degrading and punitive. Discussions about the 'good' doctors always emphasised on the friendliness of their approach, their recognition of the patient's adult status and the concordance they sought in care planning.

With reference to a wide range of evidence, Burgess *et al.* (2011) associates professionals' sense of authority with a political ideology dominated by conservatism, which in turn, determines a wide range of attitudes and behaviours. Most significantly, Burgess *et al.* (2011) associate conservatism with lower tolerance to uncertainty and ambiguity. This renders authoritarian professionals more likely to

rely on rules/clinical guidelines or cognitive shortcuts, such as stereotyping (e.g. assuming all individuals with high blood glucose to be non-compliant), thus doing away with having to look at individual differences. Therefore, they become inflexible and judgemental. This links to issues of stigma mentioned in the previous chapter. Also, with poor tolerance to ambiguity, they might feel less comfortable with biopsychosocial approaches to medicine which focus on patients' social context and less tangible approaches to care, such as relationship building. Rather, they gravitate toward the biomedical model which focuses on the management of the organic cause of disease.

Whether the development of authoritarian attitudes amongst doctors is a result of political ideology (such as conservatism) or intellectual prestige, arguments presented here, all point to the shortcomings of this attitude towards the management of chronic illness, which requires partnership in care. This is because the patient's experience of illness within a social context is as important as the expert medical knowledge of the professional, in devising care plans. Thus, it came as no surprise that participants of this study, viewed authoritarian attitudes as highly limited in providing them support for self-management.

A significant observation related to the patient-provider relationship was that despite the fact that participants were unhappy with the advice/recommendations they were given and with the lack of information they received, they often remained passive about the situation. They rarely challenged the professional except for a few who, for example, reported demanding their test results, even in a printed format. This may be part of a cultural belief that patients should take a passive role in consultations. It may also be explained in terms of lack of assertiveness on the part of patients, who had poor communication skills. The culture of passivity has been highlighted in other findings presented in this chapter, such as passivity with seeking information in general.

While passivity is unhelpful with gaining independence in self-management, the quality of care received by participants seemed to foster this unhelpful attitude. This includes the power-dominated relationships which developed during consultations and the lack of opportunities available for education, which made it harder for

patients to access information. Passivity within an authoritarian environment has been associated with collectivism by Hjelm *et al.* (2005). This author writes how collectivist cultures are generally dominated by a high degree of power distance and hierarchical relationships and individuals brought up in these cultures learn to obey authorities, implying more dependence, increased passivity and lowered self-efficacy. If this aspect of the collectivist culture is characteristic of the local scenario, this may mean that the limitations and challenges brought about by the patient-provider relationships in the Maltese healthcare system, may indeed have cultural origins.

Aspects of the local healthcare system, which seemed central to supporting or hindering self-management for participants of this study, extended beyond the follow-up visit, to include access to resources for everyday management. This subject area will be discussed in the last section of this chapter.

8.10   Access to resources

Private care only constituted a small portion of participants' out-of-pocket payment for their diabetes management. Participants also spoke about having to buy their syringes for insulin injection, their test strips for self-monitoring and sometimes their medications. For these individuals, diabetes was not just a physical burden, but also a financial one and this would often deter them from carrying out self-management as desired, such as by opting out of regular self-testing.

Information which I obtained from a health professional about self-management resources offered by Maltese Government substantiated participants' complaints about their poor access to such resources (Grixti, personal communication, November 2015). According to Grixti, a number of prescribed diabetes drugs are not part of the schedule for free drugs, although there are plans to extend this schedule. Also, although insulin is given for free, insulin analogues are only given to those with Type 1 diabetes. Insulin pens are only given to patients with Type 1 diabetes and to those with Type 2 diabetes who have significant visual problems. Furthermore, individuals with Type 2 diabetes who are on insulin are only given ten to thirty conventional syringes per month, regardless of how frequently they need to

inject. Grixti also stated that test strips for glucose monitoring are only given to individuals with Type 1 diabetes. This situation caused participants to feel poorly equipped to self-manage.

It is important to note that the above-mentioned resources were reported to have made an enormous difference in the life of some of those participants who could afford to buy them. For example, the use of insulin analogues (which are taken immediately before a meal, regardless of the meal time) gave a male participant the flexibility he desperately needed at his place of work and this changed his diabetes experience altogether. In a previous study which I conducted about the self-administration of insulin, I interviewed individuals who only self-injected once they had been introduced to insulin pens, which helped them overcome their fear of injection. These pens rendered one of these participants capable of self-injecting after long years of depending on others for this self-care activity (Buttigieg, 2003). Insulin pens are also more convenient for insulin administration when away from home, thus promoting convenience and flexibility. This seems to suggest that access to these resources may indeed be significantly important when determining coping abilities.

Another resource which participants discussed was information on diabetes, the provision of which was often felt to be lacking. This, together with a lack of information about their own test results, was felt to undermine their rights as patients and compromise their ability to manage their condition. This shortcoming needs to be considered in light of the new Health Care Act 2013, which has endorsed the Charter of Patients' Rights and Responsibilities in Malta. This states that patients have the right to receive all information which they need to gain insight into their health status, and to be able to make informed decisions about it (Azzopardi Muscat *et al.,* 2014). The acute lack of information about test results during consultations had been observed and reported in the earlier study by Formosa (2009) who conducted a non-randomised controlled trial to examine the effectiveness of the Maltese structured education programme in improving knowledge and biological markers. Formosa (2009) found that patients who participated in her study did not know when their HbA1c was taken and nor was this discussed with them during their follow-up visit.

The provision of information as part of patient education has long been regarded as an essential part of patient management in diabetes care, such that treatment of diabetes without systematic self-management education has been considered not merely as substandard but also as unethical care (ADA, 2000). Although education is not the only support required for self-management, patients cannot manage their diabetes without knowing the underlying principles. In fact, the potential contribution of patient education to self-management has been identified by patient participants in several studies across different cultures (e.g. Sturt *et al.,* 2005 (UK); Rafique & Shaikh, 2006 (Pakistan); Tabrizi *et al.*, 2007 (Australian); Furler *et al.,* 2008 (Australian). On the other hand, similar to findings of this study, a number of research projects observed poor satisfaction amongst participants about the information or education received about their diabetes (Vincent *et al,.* 2006; Turner *et al.,* 2008; Alam *et al.*, 2012). This may mean that patient expectations about education remain to be poorly understood or insufficiently addressed in health service planning.

Participants did not raise the subject of diabetes education programmes as their actual or preferred source of information and some of them did not even know that this was an option. This subject had to be brought up by myself in every focus group. While this, and other findings, may reflect a generally low opinion of structured education as a means of self-management support, this finding has to be interpreted in the light of the fact that only a few participants actually had the experience of such a programme. Invitation to this programme was reported to be extremely low. In her controlled trial mentioned above, Formosa (2009) also found that less than half her Maltese respondents had been invited to attend this programme.

Participants of this present study who had been invited to attend an educational programme, reported discontinuing their attendance. In fact, according to a health professional who is involved in these programmes, only approximately half of those who are invited actually get to attend to the first session and attendance becomes poorer along the duration of the programme (Azzopardi, personal communication, December 2015). This confirms the general lack of interest in the programme which includes six sessions, delivered by different members of healthcare team, generally

using didactic approaches to education. The effectiveness of the programme as evaluated by Formosa (2009) in her controlled trial was found to be weak, as it failed to improve biological markers and knowledge over a period of three months. These findings have to be considered in light of various limitations of Formosa's study, including the small sample size (n=100) and the lack of randomisation.

Didactic approaches to education, as are generally used in this programme, are not in line with the group discussion method, which was preferred by participants. Group discussions have been found to be the method of choice amongst participants in various other studies (e.g. Lawton *et al.,* 2005; Shakibazadeh *et al.,* 2011). Within a group format, individuals get the opportunity to share experiential knowledge and this, according to Solomon (2004) is viewed as an active approach to learning how to cope with illness. With reference to studies in the area of chronic illness, Heisler and Piette (2005) state how sharing experiences with others facing similar health challenges has been found to be effective in achieving behavioural change and better disease outcomes. Emotional benefits of group discussions have also been reported. As observed by Sturt *et al.* (2015) these may include overcoming feelings of isolation and achieving a sense of normalcy. In fact, in their literature review on diabetes distress, these authors found that educational interventions which effectively reduced distress all featured a group format. This notion of learning from shared experience has led to an increased interest in organising peer-led education programmes, such as the generic Expert Patients Programme in the UK.

One of the major flaws of the local programme is the delayed invitation of patients because of long waiting lists. Patients are invited on average sixteen months after their first follow-up appointment (Azzopardi, personal communication, December 2015). As participants of this present study pointed out, their interest to attend classes diminishes once that they get set in their ways of self-management. In fact, in their systematic review of diabetes educational interventions, Steed *et al.* (2003) found that effectiveness of interventions was highest with a shorter duration of diabetes, showing that it may get harder to change behaviour over time. Nevertheless, the problem with attending structured educational programmes seems to be a widespread phenomenon. The DAWN2 study found that less than half the

respondents had participated in such a programme, reporting a wide cross-national variation amongst seventeen countries across four continents (Nicolucci *et al.*, 2013).

As discussed in Chapter 2, although studies have shown diabetes education programmes to be effective in producing desirable outcomes, the long-term effectiveness of these programmes remains debatable. Nevertheless, structured programmes are still considered an important part of diabetes management and various national bodies and organisations, such as the British National Institute for Health and Clinical Excellence (NICE) still promote structured education for individuals with diabetes (NICE, 2011). The new national diabetes strategy for Malta makes reference to the need on improving diabetes education (Ministry of Energy and Health, 2015, p. 33). However, little is written on how this will be achieved. No further training and recruitment of health professions to manage the educational needs of patients (except for dieticians) or measures to improve referral of patients to educational programmes, are mentioned.

8.11   The general influence of the organisation of care in Malta on diabetes self-management

The general experience of health services, as identified by this study, seemed to be a negative one and findings regarding these services are similar to those obtained in other local research work. It does seem, therefore, that the provision of diabetes services in Malta may not be satisfying population needs. In fact the Euro Index 2014, set by the Health Consumer Powerhouse (HCP) to provide a comparison of diabetes management in Europe, classified Malta in the twenty eighth place out of thirty seven countries, with Malta scoring particularly low in access to treatment and care (HCP, 2014).

In the Maltese public health system, factors related to poor organisation and financing of services seem to limit individuals' opportunity to receive holistic and comprehensive care. The pattern of my findings seems to suggest that this is attributed to the fact that the whole system of care is based on the bio-medical model of health. It is unclear whether this results from the fact that the overall organisation and planning of healthcare in Malta is carried out by members of the medical

profession who hold key roles in decision making, or who act as consultants to non-health professionals who hold key positions in management. This, however, is a possible theory which could be examined in a future study.

Emphasis on the medical model may explain a number of characteristics of healthcare identified in this study. It explains why follow-up care is left solely in the hands of doctors who are considered most knowledgeable in medical management; why consultations are brief, medically oriented and driven by an authoritarian approach; why there is little effort to provide continuity of care which promotes relationship building with professionals; and even why so little effort is placed in equipping patients with resources, which enable them to be self-reliant. The system is in no way focused on patient empowerment and seems to reinforce passivity which may already be culturally ingrained in the typical Maltese patient. This overall manner by which a healthcare system, based on the medical model, has been found to impact on the quality of diabetes care has provided new insight into this subject matter. This evidence needs to be considered within the context of how global policies have responded to the rise in the prevalence of chronic illness, focusing on the way health and social services should be managed and delivered in chronic illness (Wilson *et al.,* 2012). Various chronic care models have been developed to guide service delivery, the aim being that of empowering patients in managing their chronic condition. The Chronic Care Model (Wagner *et al.,* 2001) has been highly influential in this field. The Model for Holistic Management of Chronic Conditions in Europe, devised and published as a White Paper by the European Platform for Patients' Organisations, Science and Industry (EPPOSI, 2012) also places emphasis on patient empowerment as well as on holism and inter-sectorial cooperation.

The insistence that patients are always seen by doctors during follow-up appointments, has been shown to be a cause of various shortcomings in care. The reason behind this practice may be complex and not attributed solely to authoritarian attitudes of the medical profession, who may feel that they alone are equipped with the necessary knowledge and skills. Another reason could be attributed to the fact that salaried professionals are known to work privately on a fee-for-service bases, as are various private GPs who hold a key role in diabetes follow-up care. This, in

itself, may discourage referral of patients to other health professionals, such as specialist nurses. Such referrals may interfere with the business generated by private patients. In fact, problems associated with fee-for-service payment on healthcare, have been highlighted elsewhere, with reference to the reluctance it induces among doctors, to refer patients to other health professionals (Zhang *et al*., 2012). On the other hand, as mentioned in this chapter, the feasibility of extending nurses' roles within a system dominated by power relationships would need to be investigated before initiatives towards this end are considered. These arguments point to complex systems and attitudes which govern decisions on healthcare and which may not always have the patients' well-being at heart.

Since various participants in this study have reported opting for private care, I have tried to identify whether this had any impact on their coping abilities. The pattern that emerged was that individuals who coped best were the ones who talked positively about their health professionals, whether these worked at the private or public sector, and who demonstrated good communication skills during consultations, for example, they were assertive in their request for information. Such a pattern may indicate that the patient-provider relationship is what matters most for effective self-management, regardless of the setting in which it takes place. It has also shown that communication skills amongst patients and providers are essential for this relationship to develop.

As in the previous chapter, before concluding this chapter, I will show how findings presented in this chapter could impact on the implementation of the emic DSMS. As discussed in Chapters 5 and 6, this strategy consisted of managing behaviour by being **flexible** and **planning ahead** and managing thoughts by preventing **stress** and developing a **positive mind-set**. These approaches were thought necessary for successful adaptation to diabetes.

Participants pointed to various shortcomings in their follow-up care which limited their opportunity to be cared for by a health professional who could get to know them well. This, together with the general tendency for health professionals to withhold information from patients, avoid discussion and focus on disease and pathology, are likely to inhibit patients from developing flexible and proactive

management skills. Acquisition of these skills requires collaborative relationships with health professionals, centred around holistic management. The lack of opportunity for skills development and the poor access to resources which promote flexibility, such as insulin analogues and insulin pens, also limit the application of flexibility and pro-active coping in management. Psychological management, as articulated by patients, was likely to be adversely affected by the authoritarian attitudes of some professionals who, through judging, threatening and treating patients as children, did little to promote a positive mind-set, particularly in relation to self-perception, including self-efficacy. Furthermore, poor access to health resources, which often involved financial constraints, were likely to increase stress, further compromising self-care. Figure 8.5 represents the process by which access to healthcare, as reported by participants, could impact on their success or failure to implement the emic DSMS. As in the previous chapter, this is done by linking elements of Category 2 with findings about access to health services, as presented in this chapter.
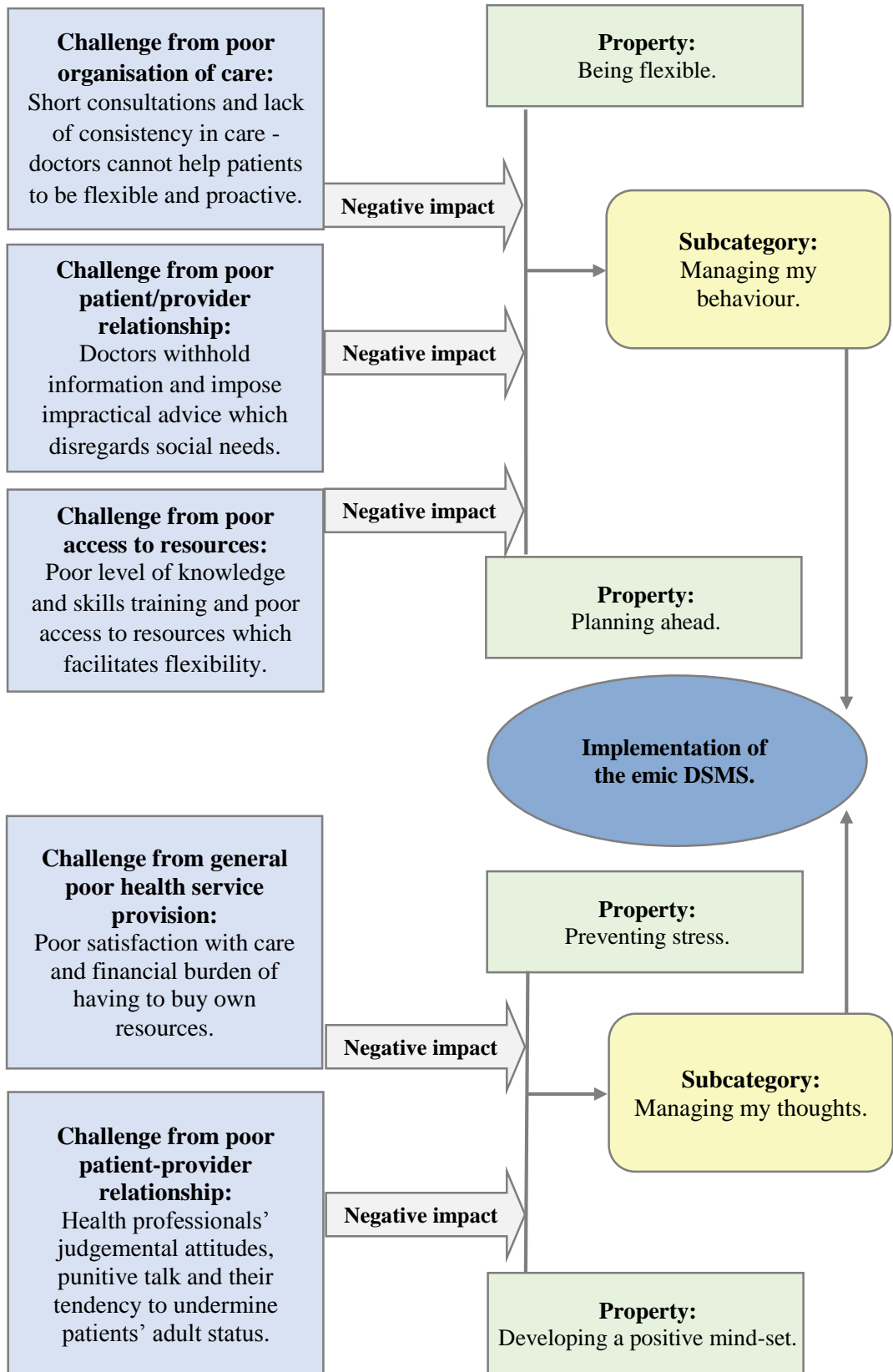
Figure 8.5   Impact of health services on one's ability to implement the emic DSMS

8.12   Conclusion

The group of findings presented in this chapter was the most difficult to discuss as they touched upon various aspects of care. Whilst it was not possible to discuss all of these aspects at any depth, it was necessary to include most of the topic areas brought up by participants since each area had a significant impact on the effectiveness of care received. Also, a comprehensive view was necessary to identify the overall pattern of organisational activity which seemed to create problems with accessibility.

Overall this chapter has highlighted the limitations of health services in Malta in supporting diabetes self-management and in providing equal access to quality care. These limitations have touched upon aspects of care organisation, patient-provider relationships and access to resources. Dissatisfaction with public services has often resulted in opting for private care amongst those who could afford it. However, despite the financial implications involved, this may not necessarily lead to better coping and in itself may continue to support the system which is creating the various shortcomings in healthcare. In fact, limitations involved in the healthcare system seem to stem from a multitude of factors dominated by issues of power and cultural attitudes among stakeholders, which are not supportive of diabetes self-management. However, participant accounts were not consistently negative and this has provided ideas of how and when things can work out.

The recent implementation of a national strategy for diabetes care has indeed been a good step forward. This chapter has highlighted areas where identified problems have been addressed in this strategy. However, sadly, the strategy still fails to address the imminent need for holistic care and patient empowerment. While detail is included on how drugs are to be increased in the Government Formulary List, and how screening for complications will improve, reference to improvement of patient education and empowerment through various organisational, deployment and training initiatives, as well as resource provision (particularly for those with Type 2 diabetes), is vague or missing. The power to make effective change may not be equally distributed among stakeholders, but a significant amount is invested in those, who like myself, can make the voice of the patient heard through conducting

research and disseminating findings. This study was partly intended for such purpose. The next chapter will draw upon the findings presented in these last four chapters to describe how these have been linked to develop a substantive theory on self-management support.

Chapter 9

INTEGRATION OF THEORY

9.1   Introduction

The preceding four chapters have presented findings related to four categories into which my data have been grouped. Each category represented different aspects of the lived experiences of Maltese individuals with diabetes. This chapter will expose and clarify the relationships existing between these categories, with the aim of proposing a substantive grounded theory of the studied experiences. This theory will, in turn, highlight areas of action which need to be addressed in order to support diabetes self-management in Malta. Overall, the chapter presents an integrated account of how Maltese culture influences diabetes self-management, through an interplay of factors within both the cultural context and the agent/player. Although the intention is to move beyond an analytical description towards a theoretical account, the relevance of the theory beyond the culture being studied (i.e. theoretical transferability) cannot be assumed.

In presenting this theory, I will not be explaining propositional relationships between different categories individually, but rather I will expose these relationships by telling the core story. A diagrammatic representation of the theory is included in Figure 9.1. In the second part of this chapter, I will position my theory in relation to other formal theories which explain social behaviour and in the final section, I will discuss how my main findings have served to support or extend existing literature on diabetes self-management.

9.2   The theory: Interrelationships between categories

In this study, Maltese participants with Type 2 diabetes projected a strong consensus about what self-management was and what it involved. Ideas clearly evolved from living with this condition in a particular culture. This experience taught participants

what works and what does not work, while cultivating their belief on the importance of 'adaptation' to diabetes rather than simply 'managing' it. For participants, adaptation meant maintaining normality and moving on with one's life, while caring for one's diabetes and this was considered as being the main objective of self-management. Furthermore, participants construed that working towards effective self-management was an obligation towards looking after their health. It was their responsibility. These ideas were reflected in how they felt accountable for self-management outcomes and in how they developed a sense of guilt when things went wrong. As participants discussed self-management, a holistic view of this concept emerged and participants presented the idea that self-management revolves around the need to achieve thought and behavioural control. Central to their idea of self-control were skills for self-management, such as flexibility, pro-active coping, stress management, positive thinking and acceptance. In this study, I have combined these skills into what I termed an emic DSMS. These central views which participants held about self-management constituted the core category 'Controlling myself, adapting to my diabetes' which is represented in Figure 9.1.

Despite these similarities in thought about diabetes self-management, the actual individual diabetes experience was strikingly varied amongst participants and this became evident at an early stage in this research. Asked how easy or difficult diabetes self-management was, participants positioned themselves within a continuum ranging from 'easy to manage' to 'struggling to manage' one's condition. This range of perceived difficulty with managing one's condition reflected different levels of coping. In Figure 9.1, levels of coping are represented by the words easy/difficult which surround the central concept of self-management. Coping was related to how successful participants were with managing diabetes through applying the emic DSMS. So, for instance, those who found it 'easy' to manage their diabetes were more likely to be flexible, pro-active and able to develop a positive mind-set about their condition, denoting the fact that the skills they developed made a positive difference in their ability to cope. These skills were less evident amongst those who felt that they 'struggled' to manage. These participants were more likely to be either rigid in their diabetes management, have no control over their behaviour, or manage haphazardly. Those who struggled to self-manage were also more likely to be stressed about their condition and to develop negative thoughts towards it, such as

through feeling restricted and different. Possibly because of these reactions, a few individuals who found self-management difficult were noted to project anger towards or to deny their diabetes. Participants' experiences in applying skills for self-management as described here, are represented in the category 'Managing my thoughts and behaviour' and the relationship between this experience and coping is represented by the yellow arrow in Figure 9.1.

Central to the development of theory were findings which explained the possible reasons for differences in diabetes-related experiences, as mentioned above. Such findings pointed towards social structures, such as family, healthcare services, and the community at large, which influenced diabetes self-management through cultural elements which characterised them. For example, participants reported being affected by society's views of diabetes, food traditions, and family dynamics, all of which constituted key cultural elements within the Maltese social environment. These factors are represented in the category, 'Being in a helpful environment' (see Figure 9.1). Participants also mentioned how socio-cultural features of the healthcare system influenced their self-management. These features affected the organisation of their care, their relationships with health professionals and their access to self-care resources. These factors are represented in the category, 'Having access to care and resources,' as seen in Figure 9.1.

Individuals' ability to self-manage was determined by the extent to which they were affected by such cultural trends. For example, some participants were negatively affected by family or by stigma, some had particular issues with accessing resources, and others had problems in their relationship with health professionals. Overall, those who were negatively affected by cultural trends were more likely to 'struggle' to manage, demonstrating less ability to master the required skills, such as flexibility and stress management. This study exposed the process by which culture affected development of these skills. For example, culturally determined power relationships between doctors and patients inhibited the role of the doctor to teach patients how to be flexible in their management; the culturally determined role of female participants within family, intensified their responsibility towards family members, thus increasing stress levels; and stigma led to avoidance of disclosure which compromised pro-active coping. These are but a few examples of how culture

hindered the development of self-management skills amongst those who 'struggled' to self-manage, adversely influencing their agency.
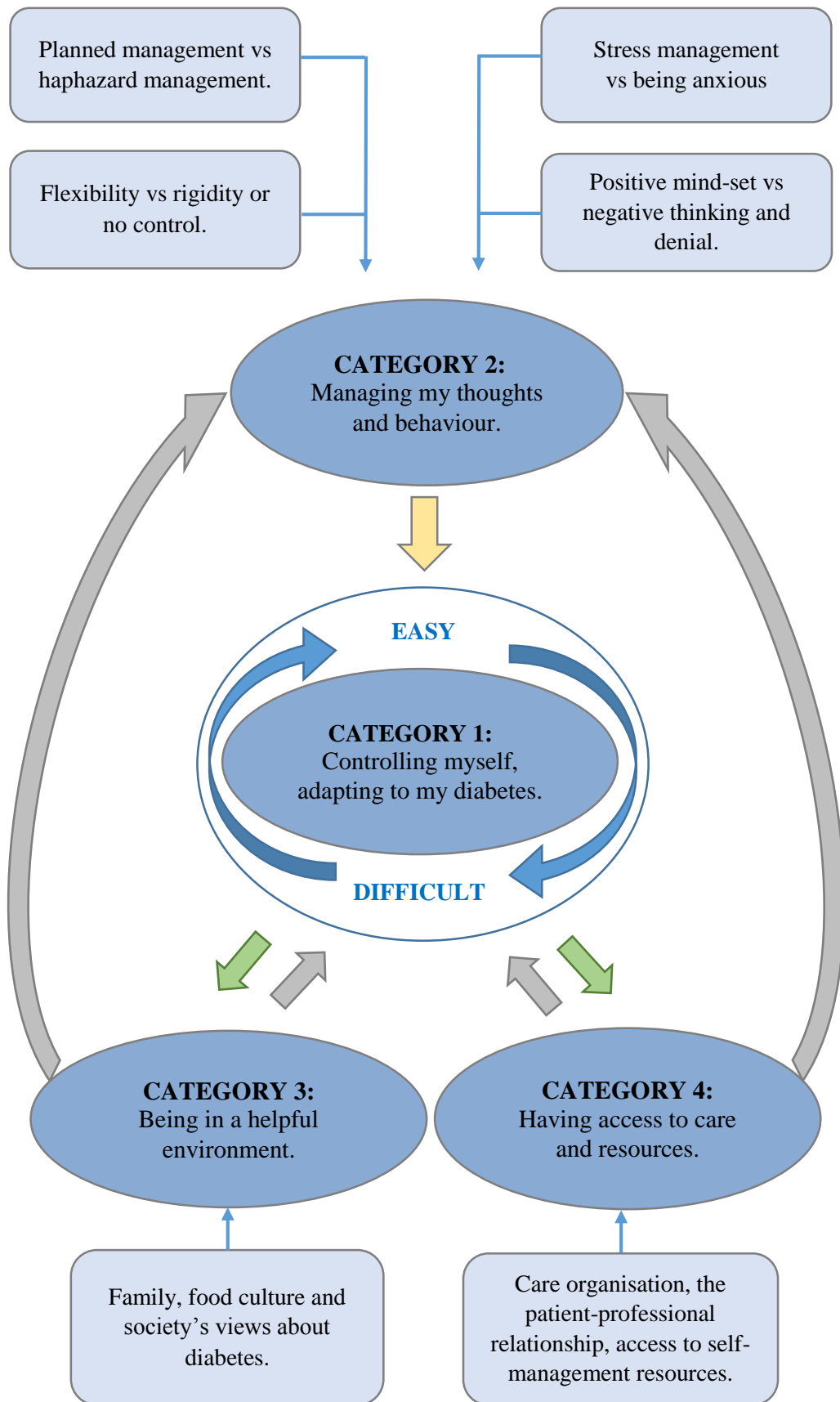
On the other hand, and very significantly, it was noted that individuals who *did* develop the required skills could better adapt to cultural challenges. So, for instance, those who managed to be flexible and proactive were better able to handle problems related to food culture than others, those who could think positively were least affected by stigma and those who developed assertiveness skills (despite cultural tendency for passivity) could overcome the problem of power differences in their patient-provider relationship. This means that while cultural trends could inhibit the development of skills for management, in the process it would also reduce the potential of the individual to overcome negative cultural influences. This creates a vicious circle of events, whereby culture threatens the development of self-management skills, which in turn, accentuates the impact of culture on individual agency. Or, seen from a different angle, culture can be considered to have a dual role in influencing self-management. Not only does it create direct challenges to management (such as through the key social role of food), but it could also interfere with the development of the actual skills which are required to overcome such challenges, such as the development of flexibility. This direct/indirect influence of culture on individual agency is represented by grey arrows in Figure 9.1. The green arrows, on the other hand, represent the individual's potential to overcome cultural challenges when equipped with the necessary skills. This illustrates how the direction of influence can indeed be two-way. This will be explained further later on in this chapter. Figures 9.2 and 9.3 then illustrate examples of the sequence of events which characterise the impact of culture on self-management.

The influence of the socio-cultural context on self-management was affirmed by the basic social process revealed through this study. In this process, individuals were found to move along different levels of difficulty with self-management across the years. Generally, they would move to a level of less difficulty as they learnt how to self-manage. However, it was also found that sometimes individuals would get stuck on a particular level or regress and move to a higher level of difficulty at some stage in their lives. This central process is represented by arrows pointing to and from 'easy' and 'difficult' in Figure 9.1. Participants' movement along this

continuum was found to be associated with experiencing a difference in social sources of support. So, for example, a young male participant started coping better with his diabetes when he changed his health professional whose practices had been highly influenced by the (culturally induced) medical model of care. His new professional was more individualised and holistic in his approach. This change was reported to make a huge difference in his life. The new doctor was pivotal in his decision to take his diabetes seriously. On the other hand, a 60-year-old female participant regressed in her management when her daughter moved in with her, bringing along her young child. The participant then started keeping sweets in her cupboard because of her grandchild. The cultural practice of keeping sweets at home for grandchildren disrupted her previous coping strategy of not buying sweets so as to avoid the temptation to eat them. Previous chapters have included other examples of how changes in context, which were related to culture, brought about changes in coping, showing the direct influence of culture on self-management.

By exposing the relationship between the social context and self-management, as described above, the emergent grounded theory has highlighted how social structures in Malta can support/hinder diabetes self-management. In so doing, it has suggested ways by which these social influences may be addressed in order to enhance the development of skills required for self-management. This, according to participant data, is central to supporting such management.

Figure 9.1 **Diagrammatic representation of the emergent substantive theory**

The diagram contains the following text elements:

- Planned management vs haphazard management.
- Flexibility vs rigidity or no control.
- Stress management vs being anxious
- Positive mind-set vs negative thinking and denial.
- CATEGORY 2: Managing my thoughts and behaviour.
- EASY
- CATEGORY 1: Controlling myself, adapting to my diabetes.
- DIFFICULT
- CATEGORY 3: Being in a helpful environment.
- CATEGORY 4: Having access to care and resources.
- Family, food culture and society's views about diabetes.
- Care organisation, the patient-professional relationship, access to self-management resources.

Figure 9.2   Cycle of events associated with the influence of culture on diabetes self-management: Example A
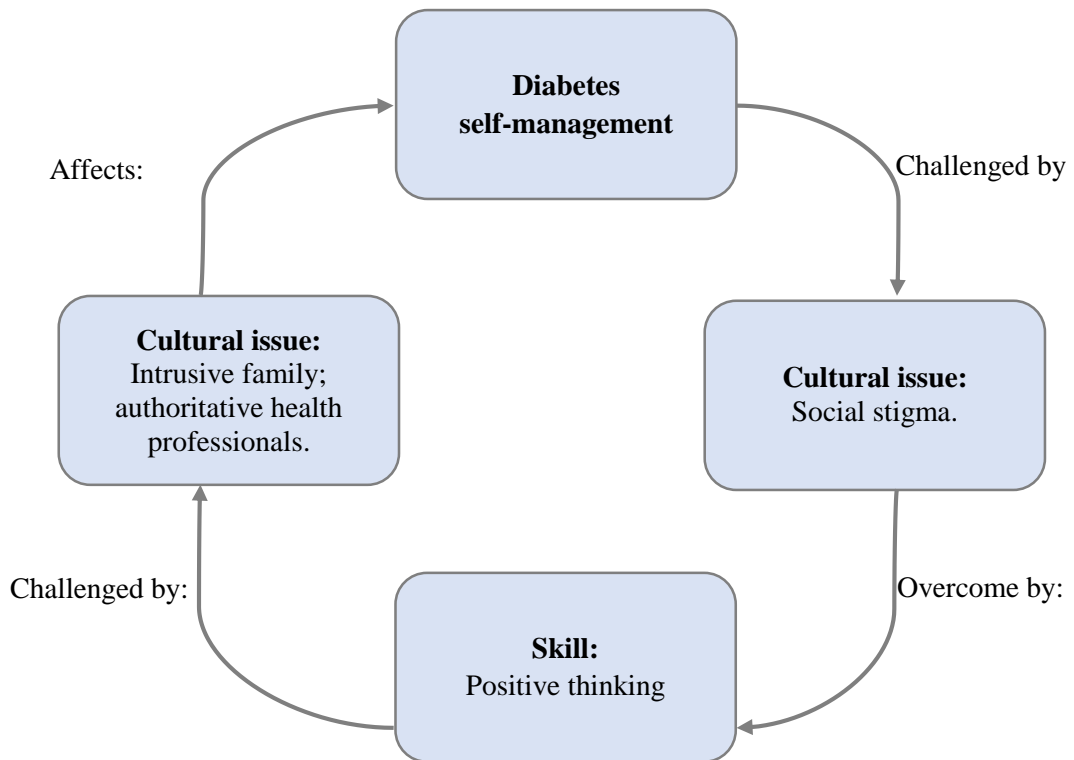
Figures 9.3 Cycle of events associated with the influence of culture on diabetes self-management: Example B

After describing the substantive theory emerging from the data, the following section will elevate this theory to a higher conceptual level, examining how it reflects theoretical explanations about human behaviour at both micro- and macro-sociological levels. In the process, it will compare this theory in relation to other more established theories.

9.3   An abstract, sociological view of the Grounded Theory

Giddens (2009) points to two sociological approaches towards studying human behaviour. He refers to the study of everyday behaviour involving face-to-face interactions, as 'micro-sociology' and the study of the impact of large-scale social systems on human behaviour, such as the cultural or political system, as 'macro-sociology.' The two different approaches are closely connected since the way in which people live their everyday life and interact with each other, is largely affected by broader social structures. As pointed out by Giddens (2009), it is often necessary to study micro-social aspects of society in order to understand the impact of broader institutional frameworks. This is exactly what this study has involved. The theory presented above has evolved through studying micro-sociological interactions but findings have shed light onto how these could be influenced by larger social structures, as will be discussed below. The following sections will address how the present theory relates to other established micro- and macro- level theories of social behaviour. This will serve as a means by which the emergent theory will be integrated with formal existing ones, this being a central feature in the application of GT Methods (Urquhart, 2013).

9.3.1   Micro-sociological explanations of self-management behaviour

During data collection, participants were asked to explain their experiences of living with diabetes. In response, they described their everyday interactions with others, highlighting how these interactions hindered or helped them with managing their condition. This study focused primarily on these interactions, although any issues outside the domain of these interactions, such as participants' direct access to resources, were also considered. As participants narrated their experiences, they described not just the social interactions they come across, but also what these

interactions meant to them, that is, their interpretation of them. They would act towards their diabetes, precisely upon these interpretations. So, for example, when a health professional praised a participant's efforts, the individual interpreted this to mean that he was doing well, that self-management recommendations were doable and that he was able to adhere to such recommendations if he put his mind to it. This interpretation may have been influenced by the fact that for the patient, the health professional was the expert in the field and therefore his judgements could be trusted. Such interaction resulted in greater striving towards self-management. This thought/behavioural process is in line with the theory of Symbolic Interactionism which was introduced in Chapter 3 as a theory which guided methods of this study.

Blumer (1969) gives three basic, widely quoted principles about social behaviour, upon which Symbolic Interaction theory is based. The first principle is that human beings' behaviour towards things is based on the meaning that such things have for them. The second is that these meanings are a product of social interaction, while the third is, that such meanings are constructed upon an interpretation of this interaction, or of the symbols used within this interaction, such as language.

As Blumer (1969) points out, meaning arises in the process of interaction between people, in that people's actions serve to define the subject of interaction for the person. However, individuals do not construct these meanings in any automatic fashion, but rather through an active process of interpretation. This is highlighted in the example of a participant-doctor interaction, given earlier. In this example, the participant acted upon his interpretation of the doctor's behaviour towards him

Blumer (1969) also refers to how social interaction creates meaning to *objects* which could be abstract and social in nature, such as family, social roles and moral principles. The meaning of these objects to the person is defined by others with whom she/he interacts. Therefore, these objects are seen as social creations. A typical example of a socially constructed object which was central to self-management of participants was the family. From their social interactions, participants developed a perception of what constituted an 'ideal' family and what their particular role should be within such families. They would then sometimes approach their diabetes according to the social expectations related to these roles.

Thus, the woman whose self-management requirements were in conflict with her socially constructed role as a mother, may have been inclined to put family first, as she felt that this was what was expected of her. The self is also an object and Blumer (1969, p.12) states, that like other objects, the 'self-object' is constructed by the process of social interaction. He continues to state that people see themselves as others see or define them. So, some participants in this study talked about themselves as devalued humans, who are inferior to others. This self-image was reinforced by the stigmatising attitude of the community at large, who ridiculed diabetes in their everyday language, who spoke about diabetes as a burden to society and who were too quick to judge and ultimately discriminate against them.

The role of social interaction in defining meaning is not considered as a straight forward process (Blumer, 1969). Interpretation of social interaction, upon which meaning is based, is complex and personal and may lead action towards unpredictable directions. Blumer describes interpretation as an active, reflective process during which individuals reflect upon both forces within themselves (such as inner drives) and external forces impinging upon them (such as social norms). Thus, as McClelland (2000) argues, though interactionists view behaviour as highly influenced by social interaction, individuals are not seen as merely passive, conforming objects of socialisation. Blumer (1969) writes that the things which are taken into account during the interpretive process include personal factors, such as wishes and wants, personal objectives, as well as individuals' image of themselves. Individuals also consider factors external to themselves, such as actions and anticipated actions of others, as well as the likely result of their behaviour. The complex nature of interpretation and the multitude of factors considered in the process may partly explain why, in this study, actions related to self-management differed amongst individuals living within the same cultural context. So, for example, while some individuals anticipated negative stigmatising reactions from the community in relation to their diabetes and decided to refrain from disclosing their condition upon these thoughts, a female participant who likewise expected and detested these reactions still decided to disclose her condition as a proactive measure in case she suffered from a hypo. The process upon which decisions for action were constructed were similar in both cases, although the ultimate behaviour was different. This means that although individuals may share the same thought

processes, the resultant differences in their behavioural intensions calls for the need to view and treat individuals differently.

The theory of symbolic interactionism has been criticised because of its small scale view of society with its focus on some aspects of social interactions, namely interpretation and meaning. It gives little attention to the influence of large scale structures, such as politics. Snow (2001) proposed broader principles about the influence of 'large' structures on social interaction which, he states, are implied by Blumer but not fully articulated. For example, Snow (2001) writes that social interaction itself, as well as its interpretation and meaning are determined by cultural elements of social environments. So, for example, in this present study, the fact that women tended to put family first in their interactions involving family, was brought about by norms related to traditional family structures which persist in Malta. These cultural norms shaped the kind of interactions that took place in relation to family, such as the kind of 'talk' about family which manifested in social discourse, and expectations from family members which were expressed. This, in turn, influenced action. This sequence of events is further illustrated in Table 9.1:
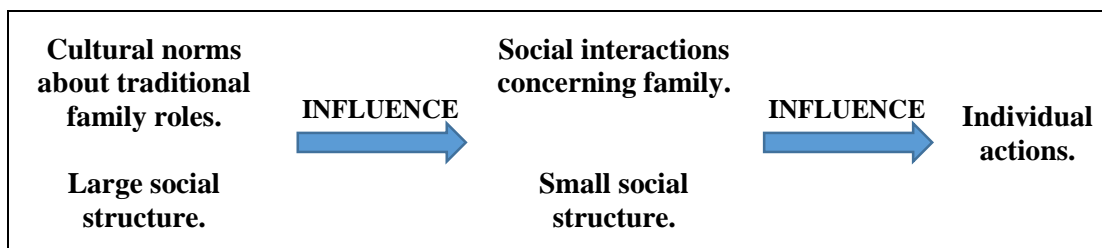
Table 9.1   The influence of large and small social structures on behaviour

Snow's (2001) extensions to symbolic interactionism have connected micro-sociological explanations of behaviour to macro-sociological ones. This connection has been clearly identified in this study, whereby social interactions and resultant meanings and behaviours have often been attributed to macro-social influences, particularly culture. A cultural element that kept surfacing was that of collectivist or individualistic ideologies which seemed to strongly influence what participants thought and did. This macro-sociological focus on my findings will be discussed in the next section.

9.3.2 Macro-sociological explanations of self-management behaviour

The individualism-collectivism divide in national cultures is one of the various dimensions of national cultures identified by Geert Hofstede (2010) in his sociological work, which examined cultural patterns across nations. Hofstede worked on data collected in the 1970s from 60,000 individuals from over fifty countries. The study examined work-related perceptions of individuals employed with IBM across the globe. Hofstede's work has been complemented for its depth and breadth and methodological rigour and his research is one of the most widely used and cited (Jones, 2007). Replications of his research have generally confirmed his results, partially or completely (Sondergaard, 1994 cited in Jones, 2007, p. 6). However, his work has also been criticised. For example, concerns have been expressed about survey methods not being appropriate for accurately studying cultural differences (Schwartz, 1999). The most frequent criticism is related to cultural homogeneity (Redpath & Nielsen, 1997) whereby Hofstede is said to assume homogenous populations when, in fact, most nations are made up of diverse ethnic groups. This drawback has minimal application to Malta since, as indicated earlier in Section 2.5.1, its population is largely homogenous.

This section will draw upon Hofstede's work regarding the individualistic / collectivist divide in cultures. According to Hofstede (2010, p. 90) most of the world population lives in collectivist societies where "the interest of the group prevails over the interest of the individual." These societies place power within the group, including the family, which is the first group into which the individual is born. In these families, which are usually of the extended type, children are taught how to think of themselves as being part of the 'we' group, distinct from other members of the society who form part of the 'they' group. This creates a divide between the 'us' and 'them.' The 'we' group becomes an important source of identity and the major source of protection for the individual. The individual develops a strong relationship with his group, together with a mutual dependence on practical and psychological support. On the other hand, amongst the minority of individuals who live in individualistic societies, "the interests of the individual prevail over the interests of the group" and individuals are normally born in nuclear families who teach them how to think of themselves as the 'I', who is distinct from

other people's 'I;' this is argued to be important in the formation of personal identity (Hofstede, 2010, p. 90). Here, individuals are taught how to be independent and are expected to leave home and reduce contact with home at an early stage in their lives. Thereafter, they remain practically and psychologically independent of their family or other group.

The main features of collectivist and individualist cultures, as mentioned above, would tend to depict the Maltese population as collectivists, considering findings of this study which have shown participants to experience strong family ties which fostered dependency. These findings have been backed up by other local research which was presented in Chapter 7. However, Malta has in fact been classified as an individualistic country by Hofstede (2010). Hofstede developed an individualism index which he assigned to participating countries and Malta was given a score of 59%, indicating a culture which is marginally individualistic. Hofstede (2010) states that other studies which have replicated his work but with more recent data resulted in similar outcomes.

Hofstede (2011) refers to individualism as reflecting modernisation of a culture and this may explain the marginal results obtained by Malta in terms of individualism. Malta is considered as an industrialised country (hence modern), however, Sultana (1994) maintains that Malta is peripheral to highly developed capitalist countries since industrialisation came later. In fact, the first phase of industrialisation in Malta took place in the period between 1950s and 1980s. A steady, but somewhat late move towards individualism, is also reflected in the way politics have evolved in Malta. For example, the dominating role of the state in the economic system, which is common in collectivist cultures (Hofstede, 2010), has been steadily declining, with the economy becoming increasingly liberalised in the 1990s and at the turn of the millennium (Briguglio, 2009).

Individualistic characteristics have also featured amongst participants in this study who perceived diabetes as their sole responsibility. This seemed to be a socially derived perspective resulting from society's moral views regarding responsibility towards health. Nevertheless, despite these individualistic trends, results from this study showed that self-management has in fact been affected by multiple collectivist

characteristics among participants. In fact, Hofstede (2011) states that various countries, such as East Asian countries, have retained considerable collectivism in spite of industrialisation, preserving such values from their history. In line with this argument, the next section will discuss how various personal and social characteristics which influenced self-management amongst participants are indeed reflective of collectivist values which have been retained by the Maltese population over the years, despite their trend towards modernisation.

An issue which has been shown to influence diabetes self-management in this study was self-perception. The manner by which participants built images of themselves, seemed to reflect collectivist trends. For example, drawing upon related evidence, Markus and Kitayama (1991) argue that in Asian collectivist cultures, individuals experience the self by relating it to others, while American individuals (who are highly individualistic) tend to focus primarily on the self, discovering and expressing their unique inner attributes in the process. The issue of relating oneself to others in developing self-perception, was very prominent in the results of this study. Individuals continuously compared themselves with those around them and in the process, constructed a self-image of being different and more restricted than others. Furthermore, those participants who tried to develop positive thoughts about themselves tended to compare themselves to more 'limited' others, such as those with more serious disease, rather than thinking positively about their own resources and abilities to self-manage. This has been found to be an unhelpful approach to positive thinking (Fournier *et al*., 2002). The tendency of relating oneself to others remained constant whether this was part of a positive or negative psychological response to diabetes. Another issue related to self-perception which was found in this study, was a lack of self-efficacy, which is probably why participants did not focus on their personal abilities when striving to adopt positive thinking. As discussed in Chapter 6, Klassen (2004) who conducted a review of twenty cross cultural studies which investigated differences in self-efficacy beliefs across cultural groups, found that beliefs about self-efficacy tended to be poorer amongst collectivist societies, characterising negative views of self. Low self-efficacy amongst collectivist cultures may be exacerbated by an inclination towards dependency.

Besides self-perception, personality issues, such as lack of assertiveness and passivity, have also been found to influence self-management in this study, affecting for example participants' behaviour during medical consultations. These attributes have also been connected to collectivist traits in research work. For example, de Mooij (2011) looking at consumer behaviour amongst fifteen European countries, found people living in individualistic societies to be more self-supporting and independent and more active in information seeking behaviour. This was not the case amongst a good number of individuals participating in this present study. Hofstede and McCrae (2004), upon studying the relationship between personality traits and different cultural dimensions amongst thirty three different countries, also found assertiveness to be strongly related to individualism. Hofstede (2010) associates this with a tendency amongst collectivists to remain at peace with one's social environment and avoid direct confrontation with others, such as by simply saying 'no.' Conversely, in individualistic cultures, speaking one's mind is considered righteous and telling the truth of how an individual feels or thinks is taken to reflect sincerity and honesty.

Maltese social life was yet another very important determinant of self-management, being characterised by a culture of eating out and socialising with food. In fact, Abela (2009) reports that compared to other EU countries, Maltese people rank high in terms of percent of their budget spent on restaurants and hotels. This social trend brought forward its own challenges to dietary control. Hofstede (2010) refers to survey data gathered from European countries which have shown that frequent socialisation in public places, such as restaurants and pubs, is significantly more common in collectivist cultures. These activities help to strengthen ties between the in-groups.

Stigma was perceived as a cultural challenge by participants and this affected their self-management in a negative and complex manner. Social theorists, including Goffman (1968), have referred to stigmatising attitudes as being related to particular socio-cultural characteristics. Rao *et al.* (2010) believe that cultural variations in stigmatising attitudes may indeed reflect the extent by which a culture invests in social connectedness. The author refers to studies which have shown an association between stigma and concerns about factors which may threaten group status and

group harmony, as being typical of collectivist orientations. Overall, as argued by Papadopoulos *et al.* (2013), individualistic cultures tend to have a stronger tolerance for deviation than collectivist cultures. The latter tend to have clearer ideas about what behaviours are appropriate and acceptable within their group. With support to these arguments, Papadopoulos *et al.* (2013) refer to a number of quantitative studies which have found stigma related to mental illness to be stronger amongst cultures known to be collectivists.

The last group of findings to be associated with collectivist traits are those related to participants' experience of medical consultations. These consultations were dominated by power relationships which determined the nature of interactions taking place within the consultation. Power distances within different societies have been widely studied and Hofstede (2011) considers this an important domain characterising cultures. He created an index for measuring power distance, which marks the extent to which subordinates or other members of society submit to authority. This index gave Malta a score of 56%, indicating an inclination towards high power relationships. Hofstede (2011) writes that countries score low in the power index when individuals in authority within their organisations, work closely with those who are not in authority, whereas countries with a high index are characterised by a more authoritarian hierarchy. Hofstede (2010) also refers to evidence which has shown that countries with a high power distance tend to be collectivists. This association is explained by Rao *et al.* (2010) who state that in individualistic societies, values are based on egalitarianism and people emphasise on equality. However, in collectivist cultures, individuals seek to obtain distinctiveness within their in-group and put substantial effort to find a good comparison with others through acquiring socially recognised forms of rank, status or power. As also found in this present study, this collectivist characteristic, together with several others, such as lack of assertiveness and passivity, can explain the nature of interactions happening within clinical consultations and which blocked the development of therapeutic relationships.

Unfortunately, findings obtained in the present study regarding collectivist and individualistic characteristics of the Maltese could not be compared to any relevant Maltese research in this area, as none could be found. However, an ethnographic

study about Maltese culture conducted by Mitchell (2002), obtained results which somewhat support those of this study. Mitchell (2002) carried out his study at a time when the Maltese authorities were discussing the integration of Malta with the European Union. He studied the core anxieties of the Maltese population related to the process of European accession, which would involve an element of 'modernisation.' His two-year fieldwork explored these anxieties through a number of areas of social life, such as gender, family, politics and ritual. He looked in particular at how a nationally important ritual, the village *festa* was used by the locals to express their anxieties about tradition and modernity. Mitchell (2002) found that the Maltese were very dedicated to their culture and in the process, showed a kind of ambivalence about modernising to become more European. Pervasive sentiments about traditional culture lead them to almost perceive modernisation and Europeanisation as a threat. In this sense, Mitchell (2002) referred to the Maltese population as having an ambivalent self-identity.

These findings relate well to those of this present study which have shown a mixture of traditional and modern values, which seem to challenge Maltese individuals from taking a clearly focused direction towards managing their health. On the one hand, they want to take full responsibility for their health, while on the other, they would like to remain passive and dependent on significant others for their care. In the midst of this ambivalence, lie multiple cultural values which seem to pull the individual towards opposing extremes of this value system. More specifically, it seems as though while participants' central beliefs about diabetes self-management were individualistic, the culture in which they had to fulfil their individualistic duties, often failed to support such approach due to fairly strong elements of collectivist trends which affected their behaviour. These trends almost rendered self-management as a collective activity, driven and shaped by social structures, such as family. This ambivalence may in itself explain why, for the majority of participants, self-management was not 'easy.'

In an earlier section of this chapter, I discussed how, in line with the micro-sociological theory of Symbolic Interactionism, participants were busy noting and actively interpreting interactions taking place around them to create their own subjective meanings upon which their behaviours would be based. Later on, in this

last section, I discussed how these behaviours could in reality have been influenced by social structures, such as culture, which determined the type of social interactions that occurred in participants' everyday lives. These social structures represented macro-sociological influences on behaviour. The overall idea has been that both individual agency (as related to the individual's subjective interpretation of life) and social structure (characterised by external objective forces) could be involved in determining action related to self-management. This combination of forces on behaviour has been effectively articulated in Giddens's Structuration Theory which focuses on both micro- and macro-sociological perspectives of behaviour. In the next section, this theory will be briefly addressed in relation to findings of this study.

9.3.3   Linking micro- and macro-sociological perspectives within the emergent theory

Giddens (1984, p. 2) states that his principle ambition when formulating the Structuration Theory was to put an end to the "imperialism" of the subject (agent) or the social structure in explaining human behaviour as is the practice in interpretive and functionalist sociological theories. Put differently, Stones (2005, p. 13) asserts that Giddens's theory avoids two important misconceptions in social thought. These are *objectivism*, which places all the emphasis on impersonal forces, such as social structures, rendering the subject as merely a 'plaything' of social systems, and *subjectivism*, which "reduces the whole of social life to the actions of individual agents or groups, their interactions, their goals, desires, interpretations and practices." In Giddens's theory, both agent and social structure are seen to have an impact on behaviour and they are considered to be interrelated and dependent on each other. In fact, Giddens (1984) states that the actions of individual agents serve to reproduce the social structures that make these actions possible. More precisely, structure is seen by Giddens (1984) to enter the essence of the agent and influence his/her behaviour. Thus, it acts as *medium* of the practices of the agent. However, structure is also the *outcome* of these practices of agents, in that collective behaviour of multiple agents, determines social structures and social norms. This is referred to by Giddens (1984) as the dual role of structure as both medium and outcome of behaviour. An example taken from the present study is how, during a consultation dominated by power relations, patients could react passively and in so doing,

reinforce the power structure of such relationship. This activity, repeated across consultations, will serve to consolidate authoritarian attitudes amongst the medical profession, which will keep fostering a passive approach from patients during consultations.

Similar to principles within Symbolic Interactionism, Giddens (1984) argues that human agents act within reason and upon *reflecting* on social structures. They reflect mainly on issues of power, meaning and social norms within these structures, while also considering their personal internal motivators. The emphasis which Giddens (1984) makes is that this reflection is only possible because of the *existence* of social structure which results from continuity and repetition of practice, as mentioned above. As Stones (2005) points out, in the process of reflection, there is always an element of interpretation. Individuals may view social structures as enabling their preferred action, or as hindering it. So, for example, some individuals considered the fact that family kept reminding them about how to behave towards their diabetes, as a means of support which helped them self-manage, while for others this was simply an act of intrusion which frustrated them. Similarly, those in this study, who were happy to be passive recipients of care and who unquestioningly believed that the doctor always knew best, were likely to view his authoritarian approach as enabling their preferred passive stance. Others, who preferred to be involved, would see authority as disabling their preference for discussion and participation. These interpretations influence behavioural outcomes such that individuals who feel that their diabetes care is being intruded upon by family, may express disagreement, and those who want to be involved in decision making during consultations may insist on having their views considered, refusing to act passively.

As Giddens (1984, p. 14) points out, as a result of their reflections, and in order to reinforce their agency, agents should always be able to "act otherwise," "to intervene in the world, or to refrain from such intervention, with the effect of influencing a specific process or state of affairs." In other words, it is always possible for agents to refrain from succumbing to social pressure, say 'no' or refuse to comply and in the process, they would make a difference. Thus, as Stones (2005) asserts, agents draw upon social structures, in order to produce actions that may *reproduce* these structures or *change* them. This is referred to by Stone (2005) as the cycle of

structuration, which has significant applicability to the present study, as will be outlined below with the use of examples. As Stone (2005) asserts, one important criticism of Giddens's theory is that it was pitched at a highly philosophical and abstract level, lacking clear links to real/practical circumstances. Stone (2005, p. 7) refers to the theory as being too 'free-floating.' In fact, despite the significant relevance of this theory to my findings, my data suggested the need to make an adjustment to Giddens's theory so that it could explain the central concepts within my emergent substantive theory. This will be explained in the next section which uses three examples from my data to explain the link between the two theories.

With further reference to the example of medical consultations mentioned above, participants who reacted passively to the authoritarian attitude of doctors, could be seen as serving to perpetuate this attitude. On the other hand, other participants used assertiveness skills to get their own views heard. In this situation, the agency of the participants brought about a change in the power-dominated context within the consultation. Taking the example of stigma, it was noted that some participants developed negative self-perceptions within a stigmatising society and as a reaction, they hid their condition from others, serving, in the process, to increase the stigmatising element of diabetes (reinforcing the social structure dominated by stigma). Other participants, using positive thinking skills, managed to preserve their self-perception, and spoke openly and factually about their condition, helping to subdue society's ideas about inferiority associated with their condition. As a final example, female participants who faithfully succumbed to the socially constructed expectations of putting family first, would push aside their health needs to see to the needs or 'wants' of their family. Using assertiveness and proactive skills, some female participants managed to achieve a balance between seeing to their own needs, as well as those of their family. Family needs were met but were not portrayed or treated as having precedence over their own (hence changing the state of affairs).

In the examples mentioned above, social structure has been seen to influence the behaviour of some participants, perpetuating itself in the process. However, when, upon reflection, elements of this structure were perceived as challenging to personal health, other individuals refused to 'comply.' What is important to note, is that this required of these individuals, the use of skills for self-management, which allowed

them to pursue their goals, despite the cultural challenges they came across. These skills, such as assertiveness, positive thinking and proactive skills, were central to their individual agency. This is an important extension to the Structuration Theory. In self-management, reflection is required for individuals to decide whether to reproduce or change structure, but skills are then necessary for individuals to 'make a difference' and these therefore are seen to have a deterministic value in the cycle of structuration. Furthermore, because skills development is, in turn, determined by elements of the social structure, as pointed in the theory emerging from this study, the cyclical link between agency and structure remains central to determining behaviour. Figure 9.3 explains the sequence of events occurring between culture and agency, this time featuring a more abstract representation of the emergent theory, connecting it to central elements of Giddens's Structuration Theory. This conceptual representation of the theory gives an important guideline for practice. In providing self-management support, it is necessary to first understand how patients interpret social forces (i.e. whether they perceive them as hindering or facilitating their self-care), and examine how these are influencing their diabetes management. We then need to help them respond to those social cues which they are unhappy about, and equip them with the necessary skills which are likely to reinforce their agency in making the necessary change.
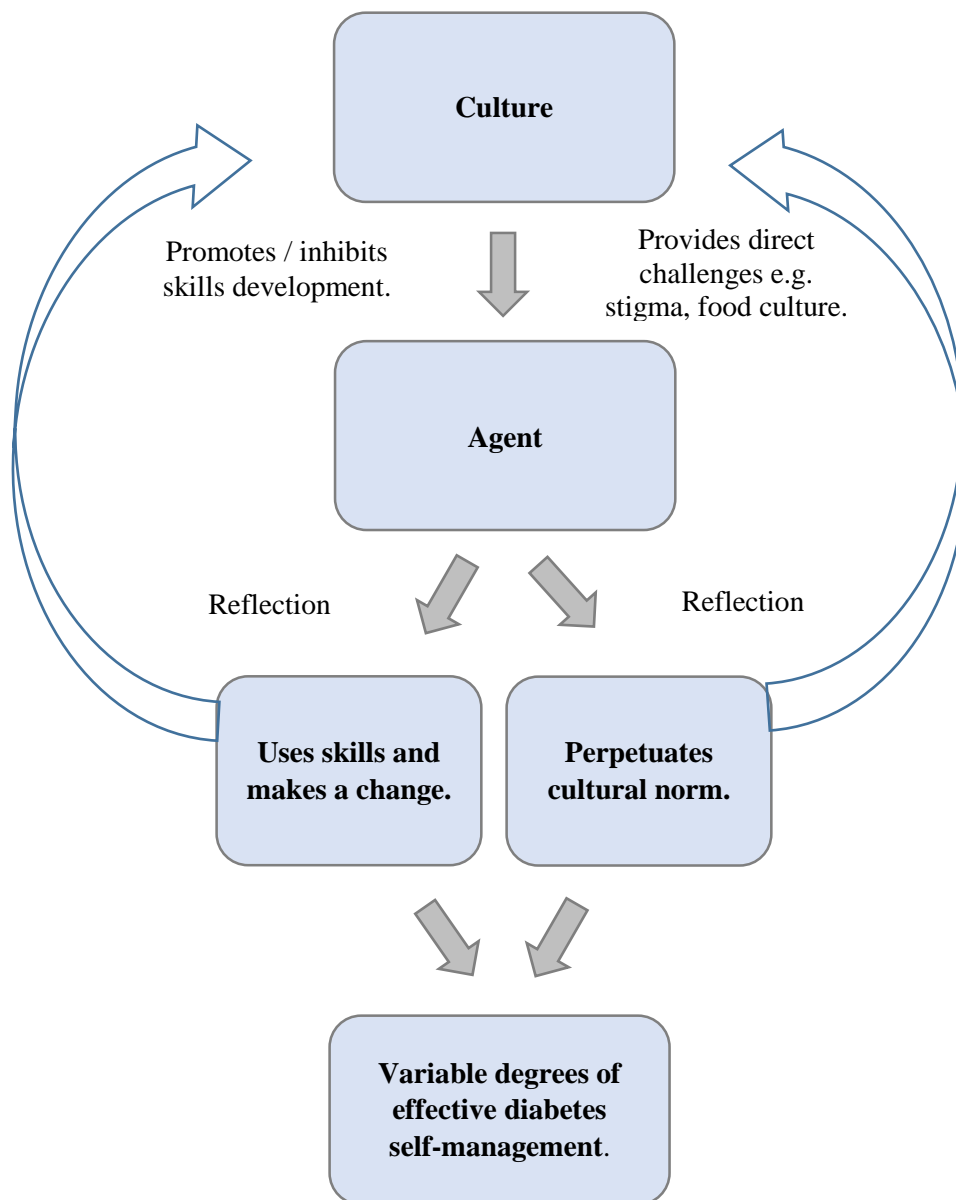
Figure 9.4   The interplay between culture and agency in diabetes self-management

This section has compared the emergent theory with extant, formal theories of social behaviour. This helped to explain central concepts within the theory and elevate it to a higher conceptual level. The section below will examine how the emergent theory and the several elements or building blocks which constructed the theory, have contributed to extending existing knowledge about the subject area under study.

9.4　　　　New insights about diabetes self-management

As suggested by Charmaz (2006), the literature review in GT is delayed for after data analysis as its scope is that of making comparisons with the literature to establish whether the emergent theory confirms, extends or contradicts existing literature. Thus, the ongoing question, as I compared my findings to the literature was as follows: Do findings of this study have anything original to offer? In reality, there were many areas of resonance between my findings and those of other studies, but there were also a number of new insights obtained. These will be addressed in the next sections, which will tackle findings presented in each of the previous four chapters. Sources of literature which my findings have been found to corroborate, have been referred to in the preceding chapters and will not be included again in this section.

9.4.1　　　　The self-management strategy and coping

In defining self-management, participants proposed behavioural and thought management skills which they felt were required to manage their diabetes. I combined these skills into an emic self-management strategy. The individual aspects of this holistic strategy have been addressed in the literature and studies have found each element (or skill) to be conducive to coping with diabetes or other chronic conditions. However, the integration of these into a strategy for self-management is new to the literature. This strategy has been found to enable coping, particularly through the strong links between its various components, which help to maintain the strategy intact. Identifying these links and the manner by which they relate and connect behavioural and psychological aspects of diabetes management together, has extended knowledge in this area of self-management. Also new to the literature is the finding that culture may indeed determine how elements of the strategy are implemented. For example, in developing positive thinking, Maltese participants were more likely to use positive yet unrealistic thinking than employ positive efficacy expectations and this was linked to aspects of their cultural environment.

The basic social process emerging from this study featured movement of participants along the coping continuum, from a level of high difficulty in coping to one less

difficult. Such patterning in one's response to diabetes management is similar to that found in other studies, and the literature associates this with learning how to cope. Evidence produced in this study has also helped to explain how individuals may revert to lower levels of diabetes-related coping during episodes in their life and indeed how movement along the coping continuum may be triggered by changes in the socio-cultural environment.

9.4.2 Influence of the social environment

Three aspects of the social environment have been found to influence self-management. These included family, stigma and food culture. Although the fact that family is central to supporting self-management is well documented in the literature, new insights have been provided into how traditional family roles may hinder diabetes self-management, with particular emphasis on gendered roles within such families. Findings related to family have, to some extent mirrored other findings obtained in non-western countries where traditional family roles are prevalent. However, the way such roles influenced both emotional and practical support have shed new light into the subject area, showing how support received from male and female partners could differ.

Literature on stigma related to diabetes is scarce, so new insights into this subject area have been substantial. Findings of this study have generally supported literature which refers to stigma as a social process involving labelling, prejudice and discrimination. The relevance of this process to diabetes has been highlighted and this has extended the literature in this area. In particular, this study has given new insight into how culture, as well as geographical characteristics of small countries such as Malta, influence individuals' coping mechanisms related to stigma, such as that of avoiding disclosure.

Maltese traditional food provides a unique challenge to diabetes management, as explained in Chapter 7. However, the challenges imposed by the use of food in celebrative occasions, are similar to those reported in various non-western countries, where individuals tend to prioritise participating in these traditional events, over adhering to their dietary regimens. Similar to individuals in these countries, food

culture for Maltese participants has proven to be a principal challenge for diabetes management, even for those with the best coping abilities.

9.4.3   Influence of health services

Negative aspects characterising diabetes-related healthcare services, as found in this study, are not new to the literature. This is despite the fact that health systems vary between countries. Problems with short consultations, lack of continuity of care, poor development of doctor-patient relationships and poor access to self-care resources have been reported in various other studies, which have been referred to in Chapter 8. This study, however, has established a lack in all these aspects within the one health system which has been studied. This has been attributed to how the whole system of care is organised around the medical model of health. To this extent, this present study has provided new insight into how such a system fails to promote patient empowerment. Findings have also extended the literature available on how systems of healthcare, which lead to more out-of-pocket payment, may adversely influence the quality of care received.

9.5   The theory: Issues of transferability

The central components of the emergent theory consist of the emic DSMS, and the influence of the cultural environment on one's ability to implement this strategy, in the process of coping. The theory also specifies the general mechanisms involved in the interplay between culture and coping. This section will highlight the extent in which these central components and mechanisms are transferable to other cultures.

1.   The emic DSMS incorporates specific skills, the effectiveness of which in relation to coping, have been studied and confirmed amongst different cultures. Consequently, it is considered that findings related to the influence of the whole strategy on self-management, are applicable to other cultures besides the Maltese one. Nevertheless, one has to keep in mind that the manner in which skills within this strategy are applied in practice, may somewhat differ between cultures and this may limit transferability.

2.   The theory identifies areas within the social environment (such as stigma, the family, food culture and the healthcare system), which

influenced self-management. Maltese characteristics of these social phenomena were noted to render their influence on self-management unique. Consequently, these findings are not considered transferable to other cultures, except to those whose social structures are similar to those found in Malta, such as where food holds a central social significance and where traditional family roles still predominate.

3.   The theory provides new insights into the mechanism by which culture influences self-management. This happens through an interplay of factors within both the cultural context and individual agency, whereby culture is seen not only as having the potential to directly challenge self-management, but also to influence the development of self-management skills which are needed to overcome these challenges. This phenomenon is new to the literature. These mechanisms of influence on self-management are considered applicable to other cultures, even though the cultural influences *per se* may differ amongst societies, as mentioned in Point No. 2.

4.   Data from which the theory has emerged has provided new insight into how a culture characterised by a mixture of individualistic and collectivist trends, as with the Maltese culture, may indeed provide particular challenges to self-management. This happens through creating an ambivalence between wanting to assume sole responsibility for self-management and opting to remain passive and dependent on others for self-care. Such findings may be relevant to specific cultures, which, as is found in Malta, have retained traditional collectivist values in the process of modernising.

9.6   Conclusion

This chapter began with explaining relationships between categories presented in the previous chapters, and in the process, it outlined the emergent theory. The theory explains cultural influences on self-management and in so doing, it highlights the support which individuals need when faced with particular cultural challenges which influence agency. Overall, the theory places importance on both culture and agency in self-management, while it describes the relationship between them.

The theory has been found to combine micro- and macro-sociological influences on self-management and to this extent it has been found to be well related to formal theories which describe both these levels of social influence on behaviour, particularly to Giddens's Theory of Structuration which combines the two levels in

explaining social behaviour. Overall, findings of this study have extended the literature on a number of aspects related to this subject area, providing new insights on both the process of self-management and the factors which influence it. Many of the findings have a significant cultural component, such that transferability of some elements of the theory may be limited only to similar cultural contexts, while others may be generally transferable. The next chapter will provide a comprehensive conclusion of the whole project and it will give details of the implications for practice emerging from these findings.

Chapter 10

CONCLUSION

10.1 Introduction

This chapter concludes this study by presenting an overview of salient issues related to its methods and results, upon which recommendations will be drawn. This involves an element of reflecting backwards and looking forward. The chapter first explains how the emergent grounded theory has contributed towards meeting study objectives. It then presents its strengths and limitations, followed by a brief outline of the implications of findings to practice, education and research. The chapter ends with a short reflection on the personal development attained as a result of completing this study.

10.2 Meeting the objectives of the study

This study used GT to explore how Maltese individuals with Type 2 diabetes constructed their meanings of self-management support. The objectives included exploring participants' own views of self-management and identifying factors within the socio-cultural context, which were construed as supporting or hindering such management. These objectives were reached by constructing a theory from participant data, which connected participants' understanding of self-management with the characteristics of the context in which diabetes was managed. This is explained in the core story emerging from findings which was discussed in Chapter 9 and which is summarised in this section.

Participants viewed self-management as involving the development of skills related to thought and behavioural management, which they felt were central to helping them 'adapt' to their diabetes. Findings showed how these skills were key to coping. The study also identified aspects of the cultural context, such as stigma, family and

the healthcare system which hindered the development of these skills. In so doing, they also reduced the individuals' ability to overcome direct cultural challenges, such as those related to food. This represented the two-way relationship between the cultural environment and personal agency towards self-management. The influence of the socio-cultural context on coping was consolidated by the basic social process emerging from findings. It was noted that individuals tended to move across different levels of coping in their life, according to their experience of the social context. They were in a better position to cope when they had supportive positive experiences and reverted back when such experiences were negative.

These findings have shed light onto what support Maltese participants required to overcome everyday challenges when managing Type 2 diabetes. The main message conveyed from participant data is that in order to support self-management, it is necessary to address cultural factors which may interfere with skills development.

The choice of methods used for constructing a grounded theory was guided by the constructivist approach to GT and by the underpinning theory of GT, that is, Symbolic Interactionism. Chapters 3 and 4 presented a detailed account of the rationale behind each methodological decision made, highlighting the associated advantages and limitations which would somehow impact on the results. The section below adopts a critical stance in presenting strengths and limitations of this study, against which the trustworthiness of its findings could be judged.

10.3   Strengths

The main strengths of this study were related to methods which ensured rigour and data quality. Procedures undertaken to achieve rigour were presented and discussed in Chapter 4. The aim was to enhance credibility, auditability and fittingness (Beck, 1993). These issues will not be repeated here. However, a couple of methodological approaches, namely negative case analysis and postponing the literature review, which were also aimed to ensure credibility of findings, will be addressed in this section, with reference to the findings of this study. Later on in this section, other general strengths which enhanced data quality, will be presented.

Lietz and Zayas (2010) refer to negative case analysis as looking out for and examining contradictory or disconfirming evidence and diverse experiences when analysing qualitative data. This helps to ensure a comprehensive exploration of a phenomenon and as such, Guba and Lincoln (1989) associate negative case analysis with credibility. In this study, contradictory evidence was presented, showing how sometimes a single or a few individuals' views varied from those of the majority. This would highlight a potential alternative way of explaining a phenomenon. For example, whilst the vast majority of participants strongly disagreed with the insensitivity with which doctors acted towards them when they failed to comply, a couple of participants were noted to feel that they deserved this approach because they had dodged responsibility towards their self-management. This gave insight into how values of self-responsibility could impact on patients' expectations from healthcare. Findings like these point to the complexity and variability of individuals' interpretation of social interaction in the process of constructing meaning. This argument is in line with central concepts within extant formal social theories, such as Symbolic Interactionism and Structuration Theory which were related to my study.

An additional methodological strength inherent in GT, and which enhanced credibility is reading the literature after data collection, allowing findings to guide the literature search. The main argument in favour of this procedure is to minimise the importation of preconceived ideas into data analysis (Glaser & Strauss, 1967). I found that delaying the literature review gave me a sense of reassurance that my theory was grounded in the data. For example, central concepts within the participants' meaning of self-management, such as flexibility and positive thinking, were addressed frequently in the literature, pointing to their effectiveness in enabling coping. It was reassuring to discover this *after* I had analysed my data. I could then be sure that this literature could not have influenced my analysis as it was only referred to once my related findings had emerged.

Besides ensuring rigour, methods used in this study, particularly those related to recruitment and data collection, were aimed at enhancing data quality. In fact, I consider the richness of my data as the key strength in my theory development. The procedures I followed included the use of cultural sensitivity during data collection. For example, during focus groups, individuals were provided with the opportunity

not to reveal their names since the underlying confidentiality was known to be a sensitive issue amongst Maltese people. This, together with my repeated contacts with participants before the interviews and the fact that I allowed participants to get to know each other during snack time before focus groups, helped participants to build trust in me and in each other. This made them feel comfortable to discuss their experiences and to even refer to the most sensitive issues during these interviews. The positive group dynamics which often developed and my emerging skill as a qualitative researcher were also fruitful in collecting rich data. Factors such as providing parking permits, directional maps, a token and last minute reminder, helped ensure a good turnout for focus groups, thereby enhancing the data collected. The quality of data was also enhanced by the combined use of focus groups and one-to-one interviews, which complemented each other in establishing breadth and depth in the study of phenomena. Finally, theoretical sampling procedures also ensured suitability of data to the emerging theory. These procedures were discussed in Chapter 4.

As suggested by Bryman (2008), the methods of data collection evolved during the study, thus maintaining the necessary flexibility required to enhance quality data. This included, for example, recruiting only females for the last focus group after the recruitment of mixed gender groups was found to be deterrent to the collection of data from female participants. Writing memos after each focus groups and interview (Charmaz, 2006) helped me to reflect on the outcomes of my recruitment procedures and interviewing skills. I used the lessons learnt to improve forthcoming data collection. In line with the views of Erlandson *et al.* (1993), I was able to identify trends, such as which invitees were declining to participate. This helped me understand the potential influence of these trends on my data. Finally, the sample itself was considered a strength, as it represented a good range of demographic and clinical characteristics.

Despite my efforts towards ensuring rigour and richness of data, a number of drawbacks were inherent in my methods and this adversely affected the nature of my data, its analysis and the transferability of my theory. These will be explained in the next section.

10.4　　Limitations

A central belief underpinning the constructivist approach to GT is that data derived within social contexts is co-constructed between the researcher and participants (Charmaz, 2006). In view of this, I was aware that my personal attributes, including my preconceived ideas about the topic area, could impact both on the data collected and its analysis. I was also conscious of the fact that participants could be selective in which data they presented me with, according to their perceptions of me, based on factors such my occupation and social status.   Thus, reflexivity became indispensable to reduce (but not totally cancel) the imposition of my views and of my personal characteristics on the data.   This issue was discussed at length in Chapter 4.

Ironically, while my data collection procedures were instrumental in enhancing data quality, my sampling methods imposed significant limitations on the type of data I collected. For example, I chose participants amongst those who came for their appointments at various diabetes clinics and ultimately recruited those who accepted to participate. This imposed a number of conditions on my data. First, it excluded those who did not attend for follow-up visits and these might have been different from attendees in terms of, for example, motivation for self-care. It also excluded those who had problems with participating, especially in a focus group and these problems were often noted to be social in nature. In fact, I found it most difficult to recruit participants from a health centre situated in a particularly deprived area, where most of those who declined to participate reported social limitations, such as having to look after a sick or disabled spouse. On the other hand, there were some advantages in the way I selected participants. For example, I recruited individuals from both the hospital clinic and health centre clinics, knowing that those attending these clinics are different in terms of their diabetes control (see Section 8.7.1). Also, I chose health centres from different parts of Malta, making sure that areas associated with different socio-economic groups were included. The fact that I did not recruit volunteers, which is the method often used in studies examining diabetes support needs, was also considered as a strength.

An issue which might be seen as a limitation, particularly if viewed from a positivist perspective, is the way I examined (as opposed to 'measured') coping. This was explored from participants' perceptions of how easy or difficult it was to manage or adapt to their diabetes. While those who found diabetes management 'easy' were also likely to be the ones who would manage proactively, apply flexibility and demonstrate positive psychological responses to their condition (indicating good coping abilities), these factors were not compared against any biological markers. This means that individuals who seemed to cope well, could still have had problems with normalising their blood glucose level. A factor indicating that this was unlikely is that those who reported problems with keeping their blood glucose within normal range, would normally refer to this as a frustrating experience, rendering their self-management a difficult task, as opposed to being 'easy' (see Section 5.4.1).

It is noted that the use of GT often ends up in the production of low-level theories which provide a detailed explanation of an area which cannot be extended or be transferable to other areas (Charmaz, 2006; Urquhart, 2013). The scope of this study was, in fact, to produce such a substantive theory which would reflect the situation within the Maltese cultural context. Nevertheless, efforts have been made to 'scale up' the theory, such as with developing progressively abstract categories (Strauss & Corbin, 1998) and ultimately, with relating and positioning my emergent theory within other extant formal theories (Urquhart, 2013). This situated my study into a wider explanatory context, which assisted its transferability. In fact, as pointed out in the previous chapter, elements of the emergent theory were considered as being transferable to cultures other than the Maltese. However, the theory as a whole remains generally substantive, reflecting a "tangible phenomenon in a clearly defined situation" (Glaser and Strauss, 1967 p. 156). The strength of the theory can, on the other hand, be judged by relating it to the widely quoted criteria for evaluating grounded theories which were developed by Glaser and Strauss (1967) and reaffirmed by Glaser (1978). According to Glaser (1978), a robust theory must be grounded in and **fit** the data from which it emerges, it must **work** by explaining behaviour in a substantive area, it must be **relevant** in that it focuses on a core concern or process, and ultimately it must be **modifiable** in that it can be altered to ensure continuing relevance to the social context from which it emerges. It is

deemed that the emergent theory *does* meet these criteria, based on the way it has been developed and its resultant characteristics.

Despite its various limitations as discussed above, this study has stimulated some thought about how self-management could be better supported within a Maltese environment. These implications are addressed in the section below. Following this, implications for further research are addressed.

10.5   Implications for management, practice and education

In their meta-synthesis of literature on diabetes self-management, Gomersall *et al.* (2011) found that amidst individualistic attitudes towards diabetes self-management, the cultural impact on such management seems to be overlooked. The authors argue that emphasis on the role of the individual may downplay the influence of cultural, material and spatial factors on self-management. That is, an extreme focus on individual responsibility may be counterproductive to addressing holistic needs of patients. This phenomenon has, to some degree, emerged in this study. Participants held what was viewed to be a socially constructed belief about self-responsibility for their diabetes management. At the same time, they did not seem to be supported to face cultural challenges which were rendering self-control problematic.

The general implication of the arguments put forward above, is that supporting self-management requires addressing negative cultural influences on such management, in order to help patients retain full participation in their healthcare. The idea is obviously not to change culture, or even to discourage individuals from participating in cultural activities. Neither should we assume fatalistic views on the cultural influence on self-management. Although cultural influence often proved challenging, participants were also noted to be happy with how some of these influences shaped their diabetes management. For example, a number of male participants felt satisfied and supported when their wives took complete responsibility of their medications and some women practically 'boasted' of their husband's involvement in their insulin treatment. If this is accepted by patients and relatives, it would be unreasonable to strive to change the state of affairs, even though it fosters dependency. The aim would be to organise diabetes care *around*

these cultural trends, preserving their supportive element, whilst enhancing patients' abilities to overcome areas of perceived cultural challenge. The main solution thus lies in a culturally sensitive healthcare provision. This has various implications for diabetes care and management in Malta, and these will be described in the following sections.

Findings of this study have shown that the current healthcare system in Malta is often failing to meet physical and psychological needs of patients with diabetes. As stated by Wagner *et al*. (2001) when current systems of healthcare do not function well, trying harder within these systems will not work; changing the system will. Diabetes care services in Malta need to shift from a focus on the medical model to one which is more suitable for the care of patients with chronic illness, and this involves re-organising the present approach to care and service provision. In the following sections, I will propose how this re-organisation can be implemented. The overall aim should be that of promoting patient empowerment whilst maintaining a holistic orientation to care.

In line with the argument put forward above, I will structure my recommendations around the Chronic Care Model (CCM) (Wagner *et al*., 2001). This was developed in America in the mid-1990s by drawing upon evidence of successful strategies for the care of chronic illness. The evidence drawn pointed to the need of developing programmes which increase patients' knowledge, skills and confidence in self-management, and this is the principle upon which the CCM was structured (Wagner, 2001). This is in line with findings of this present study which highlighted the central role of these elements in self-management. It is for this reason that I have chosen this model to provide a framework for my recommendations. The CCM was further refined in 1997, and in 2003 it was updated to include advances in the field of chronic care (Improving Chronic Illness Care Team (ICIC), 2016). The model has guided chronic care programmes in the United States and around the world and evidence has supported the use of CCM as an integrated framework to guide service development (Coleman *et al.,* 2009). As these authors report, although more evidence is needed in areas such as cost-effectiveness, these studies suggest that using the CCM to design care leads to better services and health outcomes.

The CCM covers six areas of service provision and evidence has shown that none of these areas implemented on its own will lead to substantial improvement in quality of care (Wagner, 2004). Rather, a comprehensive approach to change is required. These elements will be examined against evidence emerging from this study and will be used to guide proposals for improvements in practice, policy and education. In the following sections, the main recommendations for change are highlighted using a bold font.

10.5.1 Element 1: Self-management support

Principally, the model suggests that support for self-management should be ongoing and provided by practice teams, family and friends. It should therefore incorporate supportive follow-up care which is backed up by structured education, and helpful social environments. The former two sources of support will be addressed separately in this section while support from the social environment will be addressed later on in the section entitled 'Community Resources.'

10.5.1.1 *Follow-up care*

The main focus of the CCM is patient-provider interaction. In this study, this clearly emerged as a central feature in self-management support. According to the model, effective interactions are needed to carry out the clinical and behavioural work entailed in chronic illness management (Wagner, 2001). Besides examining patients' clinical status, the model suggests some additional approaches. During interactions, health professionals should assess self-management skills and confidence, as well as review patients' perspectives of their management. They should also help patients set goals and solve problems which might arise when attempting to achieve these goals. As indicated by Wagner *et al.* (2001), this collaborative approach is likely to result in a feasible and acceptable shared plan of care. Whilst this is in line with participants' general expectations from a consultation, findings of this study suggest that this would require **changes in the way health professionals presently manage their encounters with patients.**

This study highlights the need for more questioning and information-giving to enable both patient and professional to make the right management decisions. Also, more attention to the patients' social context would render goals more realistic and help patients apply flexibility and pro-active management, which are central to problem solving. There is also a need for more sensitive communication which fosters positive thinking amongst patients, as well as confidence in achieving goals. These changes would require a **re-organisation of follow-up care** such that consultations are longer, and feature continuity of care given by the same health professional. This would enable the development of a therapeutic patient-provider relationship. Besides enhancing safety and promoting trust, this relationship enables healthcare professionals to examine individualised needs, such as those arising from patients' own interpretations of cultural influence on their management.

The above mentioned changes in patient-provider encounters require that health professionals possess specific skills to be able to promote self-management and that they adopt a more positive attitude towards patient empowerment. These changes can be encouraged through **adequate training and education of these professionals**. The WHO (2005) has developed a set of competencies required by health professionals involved in the care of patients with chronic illness which include competencies for delivering patient-centred care and for working in partnership with patients and other providers. This could serve as a guide for training health professionals in Malta.

Ongoing support for self-management also involves the **provision of self-management resources.** There is need for more financial investment in this area, as feasible within existing financial constraints. Better access to resources, such as insulin pens and insulin analogues will enhance flexible management. The provision of more types of diabetes drugs, free of charge, is a planned service and is one of the main focal areas of the new diabetes care strategy (Ministry of Energy and Health, 2015). The accessibility to health food as a self-management resource also needs to be considered. This involves not only its physical accessibility (such as in restaurants and work canteens) but also its financial one. A multi-sectorial approach towards improving access to health food would be required.

10.5.1.2   *Patient education*

Participants' accounts pointed to a lack of patient education as being one of the weakest aspects in Maltese diabetes services. A total revamp is required not only in the amount of education to be given, but also in when and how this is given. **Information and advice should feature in every healthcare encounter**, and should include feedback of results of tests and examinations performed.

Educational programmes need to be culturally sensitive, addressing cultural influences on self-management. Facilitated group discussions need to replace didactic methods of education and **emphasis needs to be placed on skills training,** including stress management, positive thinking, flexibility, problem-solving and communication/assertiveness skills. The usefulness of these skills in self-management has been discussed in the various chapters preceding this. This recommendation is in line with those included in the CCM which proposes that patient education should shift from a focus on patients' knowledge of the disease and its treatment, to enhancing their confidence and skills in management (Wagner *et al*., 2001).

Lessons learnt from foreign experiences with programmes involving social learning principles and skills training, such as the UK Expert Patients' Programme (Kennedy *et al.*, 2005), could prove to be indispensable, although adaptation to local culture would be required. **Offering educational programmes soon after diagnosis** is likely to improve their uptake and outcomes. Another issue to be considered is patients' passivity in accessing educational resources. Such **resources thus need to be made more readily accessible to all.** This may include, for example, giving patients a list of reliable website links, handing leaflets directly to patients, sending newsletters to patients' homes or providing helpline facilities.

10.5.2   Element 2: Delivery system design

Considering the complex nature of most chronic illness management, the CCM proposes the use of planned and coordinated actions of various caregivers. It is suggested that roles should be clearly defined and that tasks should be well

distributed amongst team members (ICIC, 2016). This includes increased delegation of critical tasks to non-medical members of the healthcare team, who are adequately trained and who may have more time to make sure that these tasks are completed (Wagner, 2004). This recommendation has been supported by findings of this present study which have highlighted inefficiencies of follow-up care which is left solely in the hands of medical specialists. There is an imminent need to **re-evaluate who should be involved in follow-up care and in which way.** The absence of nurses in participants' accounts was particularly striking, indicating a low level of nurses' involvement in care. The time is ripe for nurses to be given a more active role in diabetes care, even if this calls for more specialised training and amendments in the law, such as with regards to prescription rights. This would ensure **more frequent and regular patient follow-up** which the CCM identifies as being required for an ongoing patient surveillance. Also, in a situation where doctors have little or no time for patient education and skills training, a system whereby patients are referred to trained nurses for education should be in place, whether this is given individually or in a group setting.

Ultimately, much more needs to be done in relation to involving other team members, such as dieticians and podiatrists. Nutritional guidance and foot and eye screening was found to be seriously lacking. **More recruitment of dieticians and more regular appointments to foot and eye clinics** are needed to improve nutritional education and screening for complications. Coordination, communication and consultations between members of the team remains crucial to providing comprehensive, seamless care and this may involve the use of electronic forms of communication.

10.5.3   Element 3: Decision support

According to the CCM, decision support for health professionals begins with **providing evidence-based clinical guidelines** (Wagner *et al.*, 2001). In fact, this present study has shown how a lack of formal guidelines has led to inconsistencies in care, which not only baffled patients but made them lose their trust in the service provided. The model further suggests integrating these guidelines into the flow of work. This may include a point of service reminder produced by an electronic

patient information system. This could, for example, remind the provider when a specific test was last taken. This kind of decision support is bound to render follow-up care in the Maltese scenario more standardised and evidence-based.

10.5.4   Element 4: Clinical information system

The CCM model suggests the **implementation of an effective information system** which facilitates timely access to relevant patient information. Although electronic patient records are best at providing this resource, electronic disease/patient registers, despite their limitations, may still help to provide reminders and key guidelines for clinical decisions, as well as providing feedback to providers of their performance (Wagner, 2004). In the present Maltese scenario, care is often given by different physicians and shared between clinics located in primary and secondary care settings, whilst screening and educational interventions are also carried out by different personnel in separate clinics. Therefore, such an information system would facilitate coordinated care and continuity.

10.5.5   Element 5: Community resources

The model emphasises the importance of utilising community resources to support self-management. It refers to the importance of **coordinating efforts with community programmes and organisations that can complement services offered by the health system** (Wager, 2004). These may include, amongst others, community-based exercise or weight management programmes. In Malta, there is particular need to offer community-based educational programmes and to provide support groups which may be organised in collaboration with local councils, parish churches and/or the Diabetes Association.

According to the findings of this study, the most important community resource is the family, which was found to have a central place and meaning in the life of the individual. However, whilst family was generally regarded as being supportive, its involvement also had the potential to be a source of hindrance to self-management. In view of this, it is important to **assess the impact of family on the individual with diabetes during follow-up care and to include family in educational and care**

programmes, so as to render its involvement more supportive. Also, whilst the use of community resources is aimed to create a supportive social environment, this study has found aspects of community behaviour which could be disruptive. This was related to social stigma which deeply affected how individuals thought and acted towards their diabetes. **Managing stigma should be part of the educational curriculum for patients, whilst the use of the media to address this social phenomenon should be emphasised.**

10.5.6   Element 6: Healthcare organisation

This element of the model is about effective leadership and general commitment to care improvement. There seems to be a need for leaders in the Maltese scenario to consult more with different stakeholders and **power relationships between professionals should be addressed** in the best interest of patient care. The model also makes reference to the **provision of incentives for quality improvement** (Wagner, 2001). Besides investing in quality assurance programmes, in Malta this may require addressing problems inherent to having professionals working in both public and privately owned clinics. This would require controversial and bold decisions that challenge long-standing practices of a profession which traditionally wields significant political power. Also, these decisions may not be readily acceptable by individuals who are accustomed to manipulating their way through an interfusion of public and private services of their own choice, even though this has been found to compromise the effectiveness of care.

10.6   Implications for further research

This study has been originally generated from my personal observation that Maltese individuals were having problems with managing their diabetes and thus required better self-management support. At that stage, I had very little knowledge of what kind of support they required and this was related to a lack of research in this area. Therefore, I explored, at a general level, what factors were hindering or supporting patients' management. I have, in the process, identified a number of such factors. However, although I examined the processes by which these factors impinged on

self-care, the individual influences (such as that of family or stigma) need further investigation. For example, in relation to health services, while participants seemed hostile towards doctors' authoritative attitude and wished these professionals to be less imposing, it is still unclear as to how this translates into Maltese patients' desire to be participative in their care. This is especially so, considering the passive stance assumed by some participants during consultations. The question thus remains: How and to what extent do patients wish to be involved in decision making? Similar questions can be asked of other identified influences on self-management. For example, why is stigma perceived so differently amongst individuals living in the same Maltese community and how and to what extent does self-perception explain this diversity? Also, while recommendations for practice were made, further research is required to guide such practice. For example, while skills training has been proposed, the manner by which this can be integrated in individualised care and group-based education, needs to be examined and eventually evaluated.

At this point, it is important to note that although I identified relationships between different factors and coping, these relationships cannot be considered to have been 'saturated' or sufficiently clarified by data, even though some relationships unfolded more easily than others. For example, the relationship between self-management skills (such as flexibility) and coping was perhaps the easiest to examine, while relationships between various cultural factors (such as family) and coping, although evident, were generally less clear. The fact that the influence of culture on coping was complex and that interpretations of support tended to vary amongst participants, challenged me further when trying to identify patterns in my data. Hence, more study in the area of coping would not only extend the knowledge gained, but also *reinforce* understanding of pertinent cultural challenges, as achieved in this study. Also, in view of the central role of culture on self-management, as identified in this study, there is need for a greater use of ethnographic approaches to studying coping.

10.7   Reflections on personal development

In my many years in academia, this project has involved the largest commitment ever for a single piece of work and it has surely tested my reserves of perseverance.

In the process, I have grown tremendously not merely in my academic skills but in so many aspects of my life and personality.

This study was my very first experience of using a qualitative approach to investigation. The intense interaction with participants, the method of analysing and interpreting data and the involvement of abstract thinking, were all new to me and involved a paradigm shift in the research methods I was used to. The experience has not only helped me learn about new research methods, but also helped me to develop new perspectives of life in general. I now appreciate, more than I ever did, both subjective and objective ways of examining everyday situations. My focus is no longer predominantly on numbers and frequencies, but equally so, on tacit meanings of the spoken word. I find myself taking both stances in making judgements about what goes on around me. The new epistemological approach has indeed changed me from within, and for the better.

I have also obtained tremendous knowledge about the subject area of diabetes self-management, gaining fresh insight into the experience of chronic illness within cultures and especially within the Maltese culture. Indeed, I have gained more insight into the Maltese culture, learning in the process, how to appreciate the way it shapes our identity.

Perhaps most significantly, upon working on this research, I have learnt how to build resilience and perseverance into working through a relatively huge project in the midst of so many other life commitments and challenges. This is particularly so considering that I also happen to live in a culture where family ties are strong and where family responsibilities are considered a priority, and perhaps I was so affected by these trends because I happen to be female and also a mother. Therefore, there was a lot of proactivity, flexibility and assertiveness needed in the process required to complete this project. As with the participants with whom I worked, I had to learn to develop these skills throughout my journey. My supervisors' role in this learning was indispensable, as they guided me through all issues that were central to my personal development.

My whole background of research work has incrementally taught me a very important lesson about research and this learning has culminated in this project. This is related to its limitation, despite its important contribution, towards answering questions about life and science. To this extent, I feel my project has merely generated propositions which could be tested in the future. Thus, I consider it to be only as a minor, albeit a significant landmark in a possibly long journey towards learning how to support individuals to manage, or even better, to adapt to their diabetes.

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Appendix 1

THE LITERATURE SEARCH STRATEGY

A systematic search strategy was applied to retrieve literature relevant to different topic areas, from electronic sources. During each search, a number of databases were used, including Academic Search Premier, CINHAHL Plus, MEDLINE, PsychINFO, Cochrane Library and Scopus. Google scholar was also used, particularly since through this, I could find relevant articles published in the Maltese Medical Journal. Various keywords and their synonyms were used, depending on the topic area being searched. Truncation (*) and Boolean logic operators 'AND' and 'OR' were included to widen or narrow the search as necessary. An example of how I combined keywords in the strategy is given below. Language limitations were applied, focusing my searches solely on works published in English. Publication date limitations varied depending on the particular search. Generally, I did not use date limitations at the beginning of the search until I had established that recent works were enough to provide the required literature. Once this was established, I would then search literature which had been published within the past six to ten years. Normally, keywords were searched for in 'title' and 'abstract' fields. When the number of hits was too large, I would review the effect which the synonyms I used had on my search and would change or remove keywords as necessary.

An example of how I combined key words and their synonyms:

Topic to search: Perceptions on diabetes self-management support
Main key words: perceptions; diabetes; self-management; support,

Column 1: perceive OR perception* OR perspective* OR wish* OR need* OR require* OR belie* OR think OR thought* OR feel* OR expect* OR say OR express* OR report OR opinion* OR recommend* OR prefer* OR want* OR view*

AND

Column 2: Diabet*

AND

Column 3: 'self manage*' OR 'self-manage*' OR 'self care' OR 'self-care' OR adhere* OR comply OR compliance OR manage* OR control OR liv* OR adapt*

AND

Column 4: Support* OR care OR service* OR help* OR reinforce* OR encourage* OR sustain OR sustenance OR assist* OR aid OR promot* OR educat* OR train* OR program*

Appendix 2

INFORMATION SHEET:
FOCUS GROUP PARTICIPANTS

UNIVERSITY OF Hull

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar

Dear Sir/Madam,

I am a lecturer in Nursing at the Faculty of Health Sciences, University of Malta. I am presently carrying out a research project at the University of Hull, UK as part of my PhD studies. The name of the study is **'Support needs for diabetes self-management: Exploring views from Maltese individuals with Type 2 diabetes.'** The nurse at the clinic has found that you are eligible to take part in this study and you have therefore been chosen to participate. This letter provides you with information about the study, answering important questions, which you might have. Kindly read this information carefully.

What is the purpose of this study and why have I been chosen?
It is well understood that a person with diabetes needs to adapt his/her lifestyle and that this may be difficult at times. Therefore, the purpose of this study is to find out what support Maltese individuals would like to have in order to manage their diabetes. This may include support that is provided by health professionals, family and friends, the neighbourhood, as well as national policies. Because of your experience with living with diabetes, your opinions about this subject are very important to us.

Appendix 2 (cont.)

What do I have to do to take part?

You are being asked to take part in a group discussion (focus group). The group will consist of up to 10 individuals who have a similar type of diabetes as you. You will be asked about what helps you to manage your diabetes and what makes this difficult. You will also be asked to suggest ways by which you may be supported to manage your diabetes. The discussion will take place in a relaxed environment. I will be coordinating this discussion with the help of two other researchers. The discussion will take approximately 1.5 - 2hours and will be audio-recorded.

Will my taking part in this study be kept confidential?

Confidentiality about what is said in the discussion will be emphasised and everyone will be asked to keep what is said in the group to him/herself. However, I cannot guarantee that all participants in the group will keep the shared information confidential. You may choose not to state your name during the focus group discussion. Research members will handle all information in confidence and will keep to the following ethical and legal practices to safeguard your confidentiality:

- Digital recorders will be password protected and accessible only to members of the research team.
- Participants' names will not appear in any written document about the focus group discussion or in any published report.
- Data will be used only for research purposes
- All data will be stored securely and will be destroyed or deleted after the study is completed.

Do I have to take part?

It is up to you to decide. You are free to choose not to participate or to withdraw from the study at any point. This will not affect the care you receive in any way. However, your participation will be much appreciated, especially since only a limited number of individuals are being chosen to take part in this group. If you decide to take part, you will be asked to sign a consent form before the discussion begins.

Appendix 2 (cont.)

What will happen to the results of the study?
Study results may be published in journal papers or conference presentations and you will have the right to access any published material. Results may also be used to inform policy regarding diabetes-related services.

Who has reviewed this study?
This study has been reviewed and a permission to carry it out in Malta has been granted by the University of Hull, UK and the University of Malta.

Information about the focus group:
The group discussion will take place at the lecture room of the Diabetes and Endocrinology Clinic (Diabetes Outpatients Department) in Mater Dei Hospital. It will start at 5.30pm with some refreshments and will finish at about 7.00 – 7.30pm. At the end of the discussion, all group members will be given a diabetes recipe book as a token for participating. There will be free parking for all. Further information about this will be given later. If later on you decide not to participate or find that you are not able to attend for the focus group, please let me know as soon as possible through one of the following contact details.

Telephone home:	21821639
Telephone office:	23401141
Mobile:	99845463

(Please make sure you write your full name if you decide to send a message)

Address:	6 Triq 1 ta' Frar 1994, Zabbar
Email:	norma.buttigieg@um.edu.mt

If you have any concerns about this study, and would like to contact the supervisor of this project about them, his name and contact details are provided below.
Email address of the supervisor of this study:
Professor Steven Ersser: S.Ersser@hull.ac.uk

Thank you for reading this information.

Yours sincerely,

_____

Norma Buttigieg

Appendix 3

CONSENT FOR ACCESS TO PATIENT INFORMATION

UNIVERSITY OF Hull

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar
Tel nos. 21821639/99845463

Date:

CONSENT FORM

This consent form is being signed in connection with the study entitled **"Support needs for diabetes self-management: Exploring views from Maltese individuals with Type 2 diabetes,"** which is being conducted by Norma Buttigieg as part of her PhD studies at the University of Hull, UK.

I have been invited to take part in the above mentioned study I have been given information about it. I would like to participate and I am giving consent to the researcher to obtain my personal details as listed below. I understand that the researcher will call me to answer any queries I might have about the study and to confirm my intension to participate.

- Name and surname
- Age
- Address and contact number/s
- My level of education
- My occupational status
- Information about my diabetes

Appendix 3 (cont.)

Contact number/s: _____

Convenient times to call: _____

Name of participant: _____

Signature of participant: _____

Signature of researcher:

_____
Norma Buttigieg

Signature of supervisor

_____
Professor Steven Ersser

Appendix 4

FORM FOR PARTICIPANT INFORMATION WHICH WAS COLLECTED DURING RECRUITMENT

Information to be gathered from participant

Name and surname of participant: _____

Age (18 – 75 years of age)   _____

Address: _____

     _____

     _____

     _____

Occupational status: ☐   Gainfully occupied

  ☐   Not gainfully occupied

Level of education: ☐   Finished primary level of education

  ☐   Finished secondary level of education

  ☐   Finished post-secondary level of education
(e.g. Sixth Form/Junior College/Polytechnic/ MCAST)

  ☐   Finished Tertiary level of Education (University)

Duration of Diabetes (at least 1 year) _____

Type of Treatment   ☐   Diet only

  ☐   Oral hypoglycaemic drugs

  ☐   Insulin

Source of follow up care: ☐   Health centre

  ☐   Diabetes and Endocrinology Clinic

  ☐   Private care

Appendix 5

LETTER OF THANKS

Norma Buttigieg
6, Triq 1 ta' Frar 1994
Zabbar
99845463

Date:

Dear   _____

Thank you for accepting to take part in the study about diabetes. As previously confirmed, the focus group will be held on _____ at 5.30pm at the lecture room of the Diabetes and Endocrinology Clinic (Diabetes Outpatients Department). This is found at Mater Dei Hospital, on the ground floor of the Outpatients Block.

I am enclosing a parking permit, which entitles you to free parking in the area marked in colour on the enclosed map. This area is normally reserved for Mater Dei Hospital (MDH) Voluntary Services, as indicated on the sign at the entry of the parking area. Kindly write down your car registration number and put this permit on the dashboard of your car where it can be seen.

Looking forward to seeing you at the focus group.

Yours sincerely,

_____
Norma Buttigieg

Appendix 6

CONSENT FOR PARTICIPATION IN A FOCUS GROUP

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar

Telephone No.   21821639/99845463

Date:

CONSENT FORM

This consent form is being signed in connection with the study entitled **"Support needs for diabetes self-management: Exploring views from Maltese individuals with Type 2 diabetes"** which is being conducted by Norma Buttigieg as part of her PhD studies at the University of Hull, UK.

I, the undersigned, agree to participate in the above mentioned study by taking part in a focus group. I have been provided with the following information:

- The purpose of the study.
- The nature of my participation.
- My right to refuse to participate or to withdraw from the study at any point, without consequence.
- The fact that the researcher will treat the information forwarded during the discussion as confidential.
- The fact that participants' names will not be used in any formal document or publication.

Appendix 6 (cont.)

Name of Participant: _____

Participant's Signature: _____

_____

Norma Buttigieg [Researcher]

_____

Prof Steven Ersser [Supervisor]

Appendix 7

THE INTERVIEW GUIDE

Interview guide for Focus Groups

Good afternoon. I would like to thank you for taking the time to join our discussion about diabetes today. I am Norma Buttigieg, the person who has been contacting you about the study. I work at the University of Malta and I am conducting this project as part of my PhD studies. I will be coordinating the meeting and will be asking you questions. Assisting me is _____ and _____ who are my colleagues and who will be taking notes about the meeting.

In Malta, diabetes is common and the aim of this project is to see how Maltese people with diabetes feel that they can be supported to take care of their diabetes. We have therefore invited you to share your ideas about this. You have all lived with diabetes for some time and have somehow experienced the challenges which this condition may bring along with it. Therefore, your opinions about how you may be supported to take care of your diabetes are very important to us. In this discussion, there will be no right or wrong answers but rather differing points of view. Please feel free to share your experiences and views even if these differ from what others have said.

Before we start, let me share some ground rules. As you know, we are tape recording this session as we don't want to miss any of your comments. So please speak up and only one person should talk at a time. Everyone who wants to speak should have a chance. During this discussion, I would like all of you to speak about your personal experiences and about what you think. Also, please do not just address me when you speak, but rather I would like you to address each other and comment on each other's opinions and experience. The discussion should be between us all and not just between you and me.

We have put name cards in front of each of you. I would like all of us to address each other by the name on the card. Please note that even though we may quote what you say in our reports, your names will not be attached to your comments. You may be assured of complete confidentiality from our side and I urge all of you to respect confidentiality about what will be said here today. Our session will last about one and a half hours. Please remember that should you wish to withdraw from this study and leave the discussion group, you are free to do so any time.

Appendix 7 (cont.)

1. Let's start by finding out some more about each other by going around the room one at a time. Please tell us your name and how long you have had diabetes.

2. How would you describe your experience of living with diabetes?

3. Let us now talk about diabetes care. What does a person need to do to take care of him/herself when he/she has diabetes? Here, we are not talking about yourself and what you do, but what you feel should be done to look after oneself when one has diabetes.

4. Now think about yourself. How satisfied are you with the way you take care of your diabetes?

Probe: Is there anything which you would like to do better? If so, what?

5. How easy or difficult do you find caring for your diabetes?

6. There may be situations around you that affect what you do about your diabetes. What things or factors make it difficult for you to take care of your diabetes?

7. What actually helps you to take care of your diabetes?

8. We have discussed your personal experiences of caring for your diabetes. So, keeping these in mind, what do you think would make your life with diabetes better?

About educational courses:
(These set of questions would be asked when educational programmes enter the discussion):

a. What do you think about educational courses for diabetes?

Probe: How important do you think these courses are in helping individuals to take care of their diabetes?

b. What would encourage you to or discourage you from attending an educational course?

9. How [else] do you like to receive information or advice about caring for your diabetes?

10. My colleague will now summarise what we have discussed during this meeting. At the end I would like you to tell me whether you think that this is a good summary.

[After the summary]

11. So the purpose of this meeting was to identify what helps you to manage your diabetes yourself and what makes this difficult. Very importantly I wanted to learn about how you think you could be better supported to look after your diabetes. So, thinking about what has been said, is there anything important we have not discussed?

Thank you for participating,

Appendix 8

INFORMATION SHEET:
ONE-TO-ONE INTERVIEW PARTICIPANTS

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar

Date:

Dear Sir/Madam,

I would like to re-introduce myself as the co-ordinator of the study about diabetes, in which you have already participated by taking part in a focus group on _____. The name of the study is: **Support Needs for Diabetes Self-Management: Exploring views from Maltese individuals with Type 2 diabetes.'** I am conducting this research as part of my PhD studies at the University of Hull, UK. I would like to invite you to take further part in this study. This letter provides you with information about this study, some of which you have been given before. It will also give you information about your new participation. Kindly read this information carefully.

What is the purpose of this study and why have I been chosen?
The purpose of this study is to find out what support Maltese individuals would like to have in order to manage their diabetes. This may include support that is provided by health professionals, family and friends, the neighbourhood, as well as national policies. Because of your experience with living with diabetes, your opinions about this subject are very important to us. This is why you had been chosen to participate in the focus group and now again, in this new part of the study.

Appendix 8 (cont.)

What do I have to do to take part?

You are being asked to take part in a one-to-one interview with me, the researcher. The interview will again focus on your diabetes experience and on what makes this easy or difficult. The aim of this interview is to clarify or further explore some of the issues which came out in the focus group. The interview will take approximately 1 – 1.5 hours and will be audio-recorded.

The nurse who works at the clinic where you go for your diabetes check-up, will call you in a few days' time to check whether you are interested to take part in this interview. If so, I will then call you to set a date for the interview, which will be carried out at a place that is most convenient to you. If you agree to take part, your personal details, which were previously collected before the focus group (such as age and level of education) will be used again in this part of the study.

Will my taking part in this study be kept confidential?

I will handle all information in confidence and will keep to the following ethical and legal practices to safeguard your confidentiality:

- Your name will not be stated in the recording, the recording will be password protected and accessible only to members of the research team.
- Your name will not appear in any written document about this study or in any published report.
- Data will be used only for research purposes.
- All data will be stored securely and will be destroyed or deleted after the study is completed.

Do I have to take part?

It is up to you to decide. You are free to choose not to participate or to withdraw from the study at any point. This will not affect the care you receive in any way. However, even this time, your participation will be much appreciated. If you decide to take part, you will be asked to sign a consent form before the interview begins.

Appendix 8 (cont.)

What will happen to the results of the study?
Results of the study may be published in journal papers or conference presentations and you will have the right to access any published material. Results may also be used to inform policy regarding diabetes-related services.

Who has reviewed this study?
This study has been reviewed and a permission to carry it out in Malta has been granted by the Research Ethics Committees of the University of Hull, UK and the University of Malta.

Contact numbers/addresses of researcher
If later on you decide not to participate or find you are not able to come for the interview, please let me know as soon as possible, through one of the following contact details.
Telephone home: 21821639
Telephone office: 23401140
Mobile: 99845463
(Please make sure you write your full name if you decide to send a message)
Address: 6 Triq 1 ta' Frar 1994, Zabbar
Email: norma.buttigieg@um.edu.mt

If you have any concerns about this study, and would like to contact the supervisor of this project about them, his name and contact details are provided below.

Email address of the supervisor of this study:
Professor Steven Ersser:
S.Ersser@hull.ac.uk

Thank you for reading this information.

Yours sincerely,

_____

Norma Buttigieg

Appendix 9

CONSENT FOR PARTICIPATING IN A ONE-TO-ONE INTERVIEW

CONSENT FORM B: ENGLISH VERSION

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar

Telephone no. 21821639/99845463

Date:

CONSENT FORM

This consent form is being signed in connection with the study entitled **"Support needs for diabetes self-management: Exploring views from Maltese individuals with Type 2 diabetes"** which is being conducted by Norma Buttigieg as part of her PhD studies at the University of Hull, UK.

I, the undersigned, agree to participate in the above mentioned study by taking part in an interview. I have been provided with the following information:

- The purpose of the study
- The nature of my participation
- My right to refuse to participate or to withdraw from the study at any point, without consequence.
- The fact that the researcher will treat the information forwarded during the discussion as confidential.
- The fact that participants' names will not be used in any formal document or publication.

Appendix 9 (cont.)

Name of participant: _____

Signature of participant: _____

Signature of researcher:

_____
Norma Buttigieg
Signature of supervisor

_____
Professor Steven Ersser

Appendix 10

LIST OF APPROVALS OBTAINED FOR ETHICAL CLEARANCE

- **Ethics committee at the University of Malta** [Appendix 11]

- **Ethics committee at the University of Bournemouth** [Appendix 12]

- **Ethics committee at the University of Hull** [Appendix 13]

- **Chief Executive Officer at the General Acute Hospital** [Appendix 14]

- **Head of the Diabetes and Endocrinology Unit** [Appendix 15]

- **Senior Medical Officer at the Primary Healthcare Department**
  [Appendix 16]

- **Nursing Officer at the Diabetes and Endocrinology Unit**
  [Appendix 17]

- **Chairman of the Department of Medicine**

- **Data Protection Officer at the General Acute Hospital**

- **Data Protection Officer at the Primary Healthcare Department**

- **Three consultant diabetologists**

- **Four Nursing Officers at the Health Centres where participant recruitment took place.**

Appendix 11

APPROVALS FROM THE UNIVERSITY OF MALTA

1. Approval from the University of Malta dated 09.09.2011.
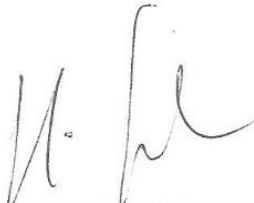2. Approval from the University of Malta dated 02.03.2012.

Appendix 11 (cont.)

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

Acceptance   **Refusal**   **Conditional acceptance**
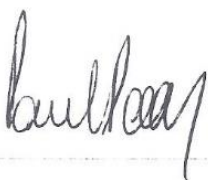
For the following reason/s:

Signature   Date 9 / 8 / 2011

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance   **Refusal**   **Conditional acceptance**

For the following reason/s:
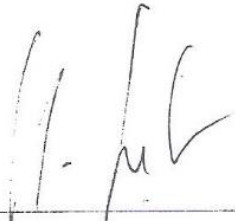
Signature   Date 9/9/11

Appendix 11 (cont.)

To be completed by Faculty Research Ethics Committee

We have examined the above proposal and advise

Acceptance   Refusal   Conditional acceptance

For the following reason/s:
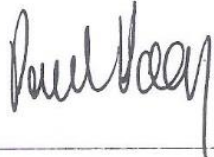
Signature   Date   15/2/2012

To be completed by University Research Ethics Committee

We have examined the above proposal and grant

Acceptance   Refusal   Conditional acceptance

For the following reason/s:

Signature   Date   2.3.12

Appendix 12

APPROVAL FROM BOURNEMOUTH UNIVERSITY

Bournemouth University

School of Health and Social Care

Research Governance Review Group

Feedback to student and supervisors

Student: Norma Josephine Buttigieg

Title; Support needs for diabetes self management: Exploring views from Maltese individuals with Type 2 diabetes

Re-review report prepared by: Martin Hind.

Date: 13.06.11

Dear Norma

Thank you for re-submitting your revised participant information sheet (PIS) to the research governance review group (RG2) in relation to required amendment stated in the report dated 03.06.11. Your study is now fully approved to proceed. Please do not hesitate to contact Martin Hind at RG2@bournemouth.ac.uk if you have any queries, or need further clarification in relation to the feedback on your study proposal.

On behalf of the Research Governance Review Group I wish you well with your study.

Yours sincerely

Dr. Lee Ann Fenge

Chair of School Postgraduate Committee

Appendix 13

APPROVALS FROM THE UNIVERSITY OF HULL

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1. Approval received from University of Hull dated 06.12.2011
2. Approval received from University of Hull dated 30.07.2012

Appendix 13 (cont.)

UNIVERSITY OF Hull

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar
Malta

**FACULTY OF HEALTH
AND SOCIAL CARE**
T: 01482 464524
E: j.kelly@hull.ac.uk

OUR REF 059
06 December 2011

Dear Norma

**Re: Support needs for diabetes self-management: exploring views from Maltese individuals
with Type 2 diabetes**

Thank you for letting me have sight of your letter and associated documentation confirming that the
above titled ethics application was approved by Bournemouth University Research Governance
Review Group in June 2011.This is sufficient for the Faculty of Health and Social Care Ethics
Committee at the University of Hull to also approve the application.

I wish you every success with your study.

Yours sincerely

Janet Kelly
Chair, Research Ethics Committee

cc.file

Appendix 13 (cont.)

UNIVERSITY OF **Hull**

**FACULTY OF HEALTH
AND SOCIAL CARE**
T: 01482 464530
E: J.Kelly@hull.ac.uk

Ms Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar
Malta

OUR REF 083
30 July 2012

Dear Norma

Re: Support needs for diabetes self management: Exploring views from Maltese individuals with Type 2 diabetes

Thank you for submitting the above proposal, with supporting documentation, that shows you have been granted ethical approval by the University of Malta Research Ethics Committee

This is sufficient evidence for approval to be granted by the Faculty of Health and Social Care Research Ethics Committee at the University of Hull, as per our Terms of Reference.

I wish you every success with your study.

Yours sincerely

Dr Janet Kelly
Chair, Research Ethics Committee
Faculty of Health and Social Care

cc: file

Appendix 14

APPROVAL FROM CHIEF EXECUTIVE OFFICER AT THE GENERAL ACUTE HOSPITAL

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar

27th April 2011

Ms Marion Rizzo
Chief Executive Officer
Mater Dei Hospital

Approved – best wishes for your project
Ullino 27/4/11

Dear Ms Rizzo

I am an Assistant Lecturer at the Faculty of Health Science, University of Malta. I am presently pursuing PhD studies at Bournemouth University, UK. My research project is entitled 'Support needs for diabetes self management: Exploring views from Maltese individuals with Type 2 diabetes'.

It is generally acknowledged that the behavioural adaptation required in the management of diabetes heavily relies on the availability of support. In fact providing support for self management is increasingly viewed as an important way of improving such management and reducing the disease burden associated with chronic illness. Therefore, the aim of this qualitative study is to explore beliefs about self management support needs amongst Maltese individuals with Type 2 diabetes.

The first phase of the study will consist of focus group research. During these group meetings, participants will be asked to reflect on what helps or hinders their self care and what support they would like to receive to self manage their diabetes. I plan to invite individuals with diabetes who attend the Diabetes and Endocrine Centre, to participate in these focus groups, amongst others. I would therefore like to request your permission to access these patients with the help of nurses working at the Department, and to ask them to participate. Information about the study, their nature of participation and confidentiality issues will be explained. All those approached will be free to refuse to participate or withdraw from the study at any point. I have been given permission by the Data Protection Officer at Mater Dei Hospital to access patient lists and files in order to obtain patient information required for recruiting participants. Permission to access patients has also been provided by Dr Mario Vassallo, Chairman of the Department of Medicine.

Thank you for your attention.

Sincerely

Buttigieg

Norma Buttigieg

Appendix 15

APPROVAL FROM HEAD OF THE DIABETES AND ENDOCRINOLOGY UNIT

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar

Date 21st April 2011

Professor Fava M.D.,M.R.C.P.(UK),F.E.F.I.M.,F.A.C.P.,F.R.C.P.(Lond.),M.Phil.,PhD
Consultant Physician, Diabetologist and Endocrinologist
Head of Diabetes and Endocrine Unit

Dear Professor Fava,

I am an Assistant Lecturer at the Faculty of Health Science, University of Malta. I am presently pursuing PhD studies at Bournemouth University, UK. My research project is entitled 'Support needs for diabetes self management: Exploring views from Maltese individuals with Type 2 diabetes'.

It is generally acknowledged that the behavioural adaptation required in the management of diabetes heavily relies on the availability of support. In fact providing support for self management is increasingly viewed as an important way of improving such management and reducing the disease burden associated with chronic illness. Therefore, the aim of this qualitative study is to explore beliefs about self management support needs amongst Maltese individuals with Type 2 diabetes.

The first phase of the study will consist of focus group research. During these group meetings, participants will be asked to reflect on what helps or hinders their self care and what support they would like to receive to self manage their diabetes. I plan to invite individuals with diabetes who attend the Diabetes and Endocrine Centre, to participate in these focus groups, amongst others. I would therefore like to request your permission to access these patients with the help of nurses working at the Department, and to ask them to participate. Information about the study, their nature of participation and confidentiality issues will be explained. All those approached will be free to refuse to participate or withdraw from the study at any point. I will be requesting a separate permission to access patient lists and files in order to obtain patient information required for recruiting participants.

Thank you for your attention.

Sincerely

I grant permission on my patients

Norma Buttigieg

c.c. Professor Azzopardi, Professor Vassallo, Dr. Cachia

Prof. Stephen Fava
MD MRCP(UK) MPhil, FACP
FEFIM, FRCP (Lond), PhD(Exeter)
Consultant Physician, Diabetologist & Endocrinologist
Mater Dei Hospital

Appendix 16

APPROVAL FROM SENIOR MEDICAL OFFICER AT THE PRIMARY HEALTHCARE DEPARTMENT

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar

22nd February 2011

Dr Grixti
Senior Medical Officer
Gzira Health Centre

Dear Dr Grixti,

I am an Assistant Lecturer at the Faculty of Health Science, University of Malta. I am presently pursuing PhD studies at Bournemouth University, UK. My research project is entitled 'Support needs for diabetes self management: Exploring views from Maltese individuals with Type 2 diabetes'.

It is generally acknowledged that the behavioural adaptation required in the management of diabetes heavily relies on the availability of support. In fact providing support for self management is increasingly viewed as an important way of improving such management and reducing the disease burden associated with chronic illness. Therefore, the aim of this qualitative study is to explore beliefs about self management support needs amongst Maltese individuals with Type 2 diabetes.

The first phase of the study will consist of focus group research. During these group meetings, participants will be asked to reflect on what helps or hinders their self care and what support they would like to receive to self manage their diabetes. I plan to invite individuals who attend Diabetes Clinics at Health Centres to participate in these focus groups, amongst others. I would therefore like to request your permission to access these patients with the help of nurses working at Diabetes Clinics, and to ask them to participate. Information about the study, their nature of participation and confidentiality issues will be explained. All those approached will be free to refuse to participate or withdraw from the study at any point. I will also be requesting permission to access patient lists and files in order to obtain patient information required for recruiting participants.

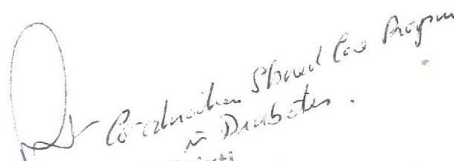Thank you for your attention.

Sincerely

Norma Buttigieg

Dr. Mario Grixti
Senior Medical Officer
Gzira Health Centre

Appendix 17

APPROVAL FROM THE NURSING OFFICER AT THE DIABETES AND ENDOCRINOLOGY UNIT

Norma Buttigieg
6 Triq L-Ewwel ta' Frar 1994
Zabbar

21st April 2011

Ms Moira Grixti
Nursing Officer in Charge
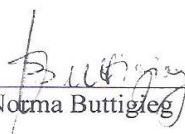Diabetes and Endocrine Clinic

Dear Ms Grixti,

I am an Assistant Lecturer at the Faculty of Health Science, University of Malta. I am presently pursuing PhD studies at Bournemouth University, UK. My research project is entitled 'Support needs for diabetes self management: Exploring views from Maltese individuals with Type 2 diabetes'.
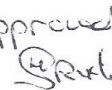
It is generally acknowledged that the behavioural adaptation required in the management of diabetes heavily relies on the availability of support. In fact providing support for self management is increasingly viewed as an important way of improving such management and reducing the disease burden associated with chronic illness. Therefore, the aim of this qualitative study is to explore beliefs about self management support needs amongst Maltese individuals with Type 2 diabetes.

The first phase of the study will consist of focus group research. During these group meetings, participants will be asked to reflect on what helps or hinders their self care and what support they would like to receive to self manage their diabetes. I plan to invite individuals with diabetes who attend the Diabetes and Endocrine Clinic, to participate in these focus groups, amongst others. I would therefore like to request your permission to access these patients with the help of the nurse working at the clinic, and to ask them to participate. Information about the study, their nature of participation and confidentiality issues will be explained. All those approached will be free to refuse to participate or withdraw from the study at any point. I will also be requesting permission for the nurse to access patient lists and files in order to obtain patient information required for recruiting participants.

Thank you for your attention.

Sincerely

Norma Buttigieg

Approved
Grixti

Moira Grixti
Nursing Officer
Diabetes Nurse Specialist
Mater Dei Hospital

Appendix 18

CHARACTERISTICS OF THE WHOLE SAMPLE OF PARTICIPANTS

Demographic and clinical characteristics:

Gender:	Male participants:	25
	Female participants:	27
Age (years):	18 – 29	2
	30 – 39	2
	40 – 49	5
	50 – 59	17
	60 – 69	21
	70 – 75	5
Educational level:	Primary	20
	Secondary	18
	Post-Secondary	9
	Tertiary	5
Occupational Status:	Gainfully occupied	22
	Not gainfully occupied	30
Duration of Diabetes (in years):	1 – 5	11
	6 – 10	19
	>10	22
Type of Treatment:	Diet	11
	OHA*	27
	OHA + insulin	10
	Insulin only	4
Source of follow-up care:	Health Centre	21
	Outpatients Clinic	31

No. of participants in just the focus groups: 40
No. of participants in both the focus groups and one-to-one interviews   6
No. of participants in just the one-to-one interview: 6

Total no. of participants: 52

---

*OHA: Oral Hypoglycaemic agents

Appendix 19

CHARACTERISTICS OF THOSE PARTICIPATING IN FOCUS GROUPS

Demographic and clinical characteristics of participants in each focus group:
Total no. of participants in focus groups: **46** [6 also had an interview]

Characteristics	Number of participants					
Focus Group Reference	**FG1**	**FG2**	**FG3**	**FG4**	**FG5**	**FG6**
Total no. of participants	**10**	**7**	**7**	**7**	**8**	**7**
Gender:						
Male participants	5	4	4	5†	4	-
Female participants	5	3	3	2	4	7
Age:						
18 – 29	**-**	**-**	**-**	**-**	**-**	**-**
30 – 39	**-**	**-**	1	**-**	**-**	**-**
40 – 49	1	1	-	-	2	-
50 – 59	3	3	2	3	2	3
60 – 69	5	2	3	4	4	3
70 – 75	1	1	1	-	-	1
Education level:						
Primary	6	4	3	3	1	2
Secondary	1	2	2	2	5	4
Post-secondary	2	1	1	1	-	1
Tertiary	1	-	1	1	2	-
Occupational status:						
Gainfully occupied	3	2	5	3	3	2
Not gainfully occupied	7	5	2	4	5	5
Duration of Diabetes (yrs)						
1 – 5	1	-	2	1	2	3
6 – 10	4	3	2	2	4	3
>10	5	4	3	4	2	1
Type of treatment						
Diet	2	5	3	-	-	-
OHA*	4	-	2	5	7	5
OHA + insulin	4	1	1	-	1	2
Insulin only	-	1	1	2	-	-
Source of follow-up care						
Health Centre	3	4	2	3	5	2
Outpatient Clinic	7	3	5	4	3	5
† - Two male participants left early.		OHA* - Oral Hypoglycaemic Agents				

Appendix 20

CHARACTERISTICS OF THOSE PARTICIPATING IN ONE-TO-ONE INTERVIEWS

Demographic and clinical characteristics of participants in one-to-one interviews.

Characteristics	Number of participants	
	Participants recruited from previous focus groups:	Participants new to the study:
Total no. of participants	**6**	**6**
Gender:		
Male participants	3	3
Female participants	3	3
Age:		
18 – 29	-	2
30 – 39	-	1
40 – 49	1	1
50 – 59	3	1
60 – 69	2	-
70 – 75	-	1
Education level:		
Primary	1	1
Secondary	1	2
Post-secondary	3	3
Tertiary	1	-
Occupational status:		
Gainfully occupied	5	4
Not gainfully occupied	1	2
Duration of Diabetes (yrs)		
1 – 5	3	2
6 – 10	1	1
>10	2	
Type of treatment		
Diet	3	1
OHA*	1	4
OHA + insulin	2	1
Insulin only	-	-
Source of follow-up care		
Health Centre	1	2
Outpatient Clinic	5	4
OHA* - Oral Hypoglycaemic Agents		