

**Illness Representations, Coping, and Psychosocial  
Adjustment: Greek-Speaking Males' Experience of Chronic  
Illness**

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**Grad.Dip.Psych., B.BSc.(Hons)**

Submitted in partial fulfilment of the requirements for the degree of Doctor of  
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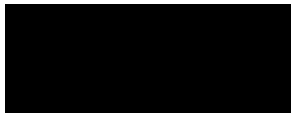
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## Declaration

“I, Stan Alexiou, declare that the Doctor of Psychology (Clinical Psychology) thesis entitled *“Illness Representations, Coping, and Psychosocial Adjustment: Greek-Speaking Males’ Experience of Chronic Illness”* is no more than 40,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work”.

Signature:



Date: 12/02/2015

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## **Abstract**

Illness representations relating to the experience of chronic illness may directly influence health and illness behaviour (coping methods), as well as having an indirect influence on psychosocial adjustment to chronic illness. Chronic illness is more than a medical condition: it is a subjective experience occurring against a backdrop of individual, social, and cultural influences that impact on the illness experience. The dynamic framework of the Common Sense Model (CSM) of health and illness makes this model particularly useful for understanding health and illness behaviours, including social and cultural factors that impact on these behaviours. The influence of illness representations on health and illness behaviours, and the processes and outcomes relating to psychosocial adjustment to chronic illness are particularly important when viewed from the perspective of culturally-diverse groups, such as the elderly Greek-speaking male participants in this study. In this thesis, participants' illness representations and coping methods for their chronic illness are explored, along with the processes and outcomes associated with their psychosocial adjustment to chronic illness. Semi-structured interviews were conducted and thematic analysis identified themes relevant to the CSM. These showed how participants' responses to their chronic illness were influenced by their personal experiences and contextual factors. Findings also identified additional themes not directly related to the CSM, revealing how participants' adjustment to their chronic illness was influenced by individual, psychosocial, and cultural factors. Implications of the study's findings include the importance for health care professionals to consider the subjective meanings of elderly male individuals' chronic illness experience, including wider social and cultural influences on their chronic illness experience, as a way of informing and establishing appropriate health care practices.

## Chapter 1

In the pursuit of scientific enquiry, the study of health and illness from a biopsychosocial perspective that tends to view patients as objects fails to capture the subjective meaning of their illness experience (Radley, 1999), such as patients' daily life with illness (Radley, 1999), from an insider's (i.e. the patient's) perspective (Conrad, 1990). This includes any social and cultural contextual influences on their experience with illness (Crossley, Nicolson, & Owens, 2001). The absence of patients' lived experience, including their views on the management of their illness, in favour of a biopsychosocial approach based on disease has led to an interest in the subjective experience of individuals with chronic illness, along with the impact of this experience on the management and psychosocial adjustment to their chronic illness.

Individuals' perceptions and beliefs regarding their chronic illness may differ from health care providers' views and understanding of their patients' chronic illness. Provider-patient differences may influence the relationship between providers and their patients and impact upon health and illness behaviours, such as patients' willingness to assume responsibility for managing their chronic illness, which may be moderated by age (Jolanki, 2009; Koch, Jenkin, & Kralik, 2004; Wrede-Sach et al., 2013) as well as cultural influences (Almyroudi, Degner, Paika, Pavlidis, & Hyphantis, 2011; Avgoulas & Fanany, 2012). Individuals' perceptions and beliefs (illness representations) may also be discordant with the reality of managing their chronic illness (coping procedures), which can have a negative influence on outcome, such as quality of life. These issues are particularly relevant for patients from different cultural backgrounds, such as the Greek-speaking males in this study.

Exploring the processes of psychosocial adjustment to chronic illness may facilitate an understanding of individuals' views of themselves and the world whilst

living with adversity (Sharpe & Curran, 2006). Literature on social influences, such as social support and social interaction, has also shown their impact on individuals with chronic illness in areas such as chronic illness self-management (Gallant, Spitze, & Prohaska, 2007) and mental health (Bell, LeRoy, & Stephenson, 1982).

The purpose of the present study was to understand the experience of chronic illness for a group of elderly Greek-speaking males residing in Australia and how this experience has influenced their health behaviours, including management of their chronic illness. In particular, to explore this group's illness representations and coping methods including the influence of their illness representations on their methods of coping. Another purpose of the study was to explore the processes and outcomes of their psychosocial adjustment to their chronic illness, including any social and cultural influences relating to their chronic illness experience. Studies have investigated illness representations of Greeks in their homeland (Anagnostopoulos & Spanea, 2005; Giannousi, Manaras, Georgoulas, & Samonis, 2010; Karademas, Kynigopoulou, Aghathangelou, & Anestis, 2010). However, the paucity of research on illness representations of Greeks in Australia contributed to the researcher's interest in this area. It is important to emphasise the influence of Greek values on behaviour, including health and illness behaviour. According to Greek Care (2013g), "Western notions of privacy, individuality, personal conscience and independent decision-making differ from the traditional Greek sense of the individual." The emphasis in the Greek culture is on the public and communal domain. Moreover, the behaviour and responsibilities of individuals within the Greek community have been governed by the expectations of immediate and extended family as well as members of individuals' broader community (village, neighbourhood, and church congregation) (Greek Care, 2013g). In relation to Greek immigrants in general, and the elderly in

particular, their identity is closely related to their behaviour within these domains (public, communal) (Greek Care, 2013g). Thus, the researcher chose to specifically explore Greek-speaking males because of a personal interest. He noticed that male members of his parents' generation appeared somewhat reticent to disclose their feelings and vulnerabilities, and he felt that an exploration of these phenomena within the context of chronic illness experience may help to elucidate the researcher's preconceived view of this groups' general reticence. The researcher felt that an exploration of the experience of chronic illness for elderly Greek-speaking males residing in Australia provided a suitable avenue to understand the potential impact of this group's illness experience, including the influence of the socio-cultural context on their illness beliefs, feelings, and behaviours, which may also help to inform health practice and may also be relevant for other Greek males residing in the wider Greek community.

An understanding of individuals' illness representations and their influence on coping procedures, together with the processes and outcomes relating to their psychosocial adjustment to chronic illness, may also help to inform and establish appropriate health care practices that also take into consideration broader social and cultural influences on patients' chronic illness experience. The dynamic framework of the Common Sense Model (CSM) of the self-regulation of health and illness (Leventhal, Brissette, & Leventhal, 2003) is particularly useful because it facilitates an understanding of cognitive and affective illness representations, including social and cultural influences, which guide coping procedures.

### **Organisation of the Present Study**

Chapter 2 presents literature on the biomedical and biopsychosocial frameworks for the study of illness and their constraints when considering the

subjective experience of illness. Studies of the subjective experience of illness are also explored along with the influence of social and cultural factors.

Chapter 3 provides an outline of the concept of chronic illness and its prevalence in Australia. This chapter also provides an outline of the nature of the chronic illness experience and the potential impact on self-identity. Non-disclosure and stigma associated with chronic illness is also discussed and studies in this area are reviewed. The concept of agency and the management of chronic illness in the context of the doctor-patient relationship are also discussed, together with a review of studies in this area.

Chapter 4 describes the Common Sense Model (CSM) of the self-regulation of health and illness (Leventhal et. al, 2003), and the usefulness of the model when applied to individuals' experience of chronic illness, including individuals from different cultural backgrounds. The model's dynamic process incorporating cognitive and affective illness representations of a health threat and the corresponding procedures and appraisals in managing the threat are described. This chapter also describes the dimensions (content) of illness representations, along with mental 'rules of thumb' (heuristics) attributed to factors other than symptoms of the illness. The influence of the self and the social environment on illness representations are also discussed. Coping procedures and appraisals of outcomes in managing the health threat are also described. Studies of illness perceptions (cognitive and affective) as well as methods of coping and outcomes for patients with chronic illness are reviewed. This chapter also describes self-regulation failure and emotion regulation that can interfere with the management of chronic illness.

Chapter 5 presents literature on psychosocial adjustment to chronic illness. A model of adjustment to chronic illness proposed by Sharpe and Curran (2006)

describes the processes and outcomes of adjustment to chronic illness. A model of response shift proposed by Sprangers and Schwartz (1999) describes the process by which a stable quality of life can be maintained despite deteriorating health. Social influences also play an important role in the adjustment to chronic illness, which can have positive and negative consequences. Social comparison processes and outcomes relating to chronic illness are described and reviewed in several studies. A conceptual model proposed by Heany and Israel (2008) is used to explain how social networks and social support are related to health. The concepts of social support and companionship and their influence on health and wellbeing are also described. Studies on the effects of social support and social interaction on the chronic illness experience are also reviewed.

Chapter 6 describes the methodology within the context of the subjective experience of illness, and includes ethical considerations and procedures related to the study's credibility. The research questions relate to a group of elderly Greek-speaking males recruited from the Greek community of Melbourne, Australia. They were designed to explore themes relating to illness representations and coping procedures based on the CSM (Leventhal et al., 2003), as well as psychosocial and cultural aspects of chronic illness (adjustment and social influences [social support, social interaction]), and are as follows:

1. How have this group perceived their illness? In particular, what themes characterise their representations of their chronic illness in relation to the cause of their illness, the consequences of their illness, and the controllability of their illness?



2. How have this group coped with their illness? Specifically, what themes characterise their coping procedures for their chronic illness?
3. How have this group's coping procedures been influenced by their illness representations?
4. How have this group adapted to their illness? In particular, what psychological, social, and cultural themes characterise their adaptation to their chronic illness?
5. How have this group been supported through their illness? Specifically, what psychological, social, and cultural themes characterised perceived support while ill?

The findings of the present study are arranged into two chapters. Chapter 7 presents the findings from thematic analysis of interviews with participants, consisting of themes of illness representations relating to the Common Sense Model (CSM). Chapter 8 presents the findings from thematic analysis of interviews with participants consisting of themes related to coping procedures as well as themes of psychosocial adjustment to chronic illness and social influences.

Chapter 9 presents the discussion of the research findings together with a review of the findings with previous research literature. The chapter also discusses the implications of the findings for the provision of appropriate health care, along with the study's limitations, and the researcher's experience of the study.

## **Chapter 2**

### **The Importance of the Subjective Experience of Illness**

This chapter presents literature on the subjective experience of illness.

Despite a longstanding interest in research on health and illness that led to the formation of the biomedical model (as outlined below), the model often overlooks the subjective experience of illness in favour of quantifying biological, psychological, and social factors that also treats patients as objects of scientific investigation (Crossley, 2000; Crossley et al., 2001; Radley, 1994). Objectifying patients' experience of illness into quantifiable measures can potentially downplay the importance of the context of their experience, as well as ignore or minimise the relevance of their beliefs, values, and perceptions. Previous literature (Crossley, 2000; Crossley et al., 2001; Radley, 1999) has explored the limitations of such models in relation to the subjective experience of illness within the field of health psychology. Socio-cultural factors can also shape individuals' subjective experience of illness, which may also influence their views about illness (Sobo & Loustau, 2010).

The present chapter begins with a brief review of the biomedical and biopsychosocial models relating to the study of illness and their limitations in relation to the subjective experience of illness. The chapter also reviews studies on the subjective experience of illness along with studies on social and cultural influences on health and illness.

#### **Patients' Experience of Chronic Illness**

The biomedical model's reductionist approach implied that illness could be reduced to biologically-related causes (Yuill et al., 2010) whereby disease was related to physical aspects of the body (Lyons & Chamberlain, 2006; Samson, 1999a) and "the human body is a machine and the doctor or surgeon is the mechanic who fixes

‘it’ when something goes wrong” (Crossley et al., 2001, p. 245). Moreover, mind and body were considered to be separate entities with the body regarded as a physical object operating separately from the mind (dualism) (Samson, 1999a). However, according to Conrad (1990), illness is a social phenomenon that is related to perception, experience, and behaviour rather than a physiological process. Moreover, an understanding of the psychological aspects of human experience as well as the relationship with the socio-cultural elements associated with such experiences appear to get overlooked when adopting a positivist approach, such as the biomedical model (Engel, 1977; Yuill, Crinson, and Duncan, 2010). Engel's (1977) biopsychosocial model evolved from a need to account for the psychological and social influences of health and illness beliefs and behaviour. Nevertheless, the biopsychosocial model's quantitative focus failed to highlight what daily life is like for individuals with illness (Radley, 1999) by allowing individuals the chance to reflect on the subjective meaning of their experience of illness (Crossley et al., 2001).

Engel (1977) also believed that the biomedical model failed to consider the patient, the social context in which the patient lives, as well as the roles of the patient's health care system and health care providers. According to Conrad (1990), ill individuals' status as patients tends to ignore the way they manage their daily life with illness. Furthermore, an outsider's perspective of illness has a tendency to exclude the illness experience by “minimizing or ignoring the subjective reality of the sufferer” (Conrad, 1990, p. 1259), which differs from an insider's perspective concerned with ill individuals' “subjective experience of living with and in spite of illness” (Conrad, 1990, p. 1259). When human beings are studied as objects, the importance of meaning for the individual is ignored. The person's own cognitions, emotions, and interpretations interact, often in complex ways, to influence the way in which the

person interacts in the world (Crossley et al., 2001). Patients' perspectives need to extend beyond the medical setting, including their doctor-patient relationship, to explore the management of their illness as well as their lives with illness in other contexts, such as their home and workplace (Conrad, 1990).

A qualitative approach provides an opportunity to explore complex and ambiguous aspects of illness, which may otherwise be neglected in a quantitative enquiry, and to obtain rich information through an exploration of the human experience, which includes the socio-cultural context (Crossley, 2000). Health and illness are understood within particular social and cultural contexts and create misunderstandings when these concepts are examined without taking such contexts into account (Crossley, 2000), or when the illness experience is not considered from an insider's perspective (Conrad, 1990). Thus, it appears that the biomedical and biopsychosocial models may be limited and researchers (Conrad, 1990; Crossley, 2000; Crossley et al., 2001; Radley, 1999) have argued for other approaches that take into account the subjective experience of illness as well as socio-cultural factors that can influence the illness experience. Studies based on qualitative approaches have developed insight into the subjective experience of illness. These studies also imply a need for a broadened biopsychosocial approach to illness taking into account other aspects of patients' illness experience, including psychosocial and contextual influences. For example, a previous study (Kaba et al., 2007) with a Greek-speaking population provides an insider's perspective (Conrad, 1990) on Greek haemodialysis patients' lived experience with chronic illness (end-stage renal disease). This study was also relevant for one of the present study's participants who was diagnosed with end-stage kidney disease.

Kaba et al. (2007) explored the lived experience of elderly Greek end-stage renal disease (ESRD) patients receiving haemodialysis. Patients endured multiple symptomatic problems with haemodialysis, including sleep deprivation and heart problems, in order to continue living. Their restricted food and fluid intake prevented social engagement with friends and family because of concerns of being tempted to forgo their dietary and fluid adherence. Forgoing the enjoyment of food is an important lifestyle change, given its importance for Greek people. Patients also experienced uncertainty with progressive illness deterioration, with transplant not an option, including anxiety about possible future problems or premature death. Their dependence on life-sustaining equipment in a familiar and safe place was viewed as a lifeline, despite their dependence on caregivers for their haemodialysis. Many patients experienced negative emotional responses (anger, denial, depression), and suicidal thoughts, from limitations and restrictions imposed by their illness. On the other hand, some patients discovered enjoyment in many aspects of life and were more relaxed with their illness, including feeling optimistic in managing their illness and determined to face the future (Kaba et al., 2007).

Meta-syntheses analyse and synthesise qualitative studies to develop themes that provide an in-depth understanding of the phenomenon in question, in this case, the lived experience of chronic illness. Two meta-syntheses on the lived experience of illness (Bayhakki and Hatthakit, 2012; Siabani, Leeder, and Davidson, 2013) are presented, which include the influence of the social environment and factors relating to self-management. These studies were also relevant for several participants (Bill, Peter) in the present study who had similar chronic illnesses (i.e. end-stage kidney disease [Bill]), chronic artery disease [or chronic heart disease] [Peter]).

A meta-synthesis by Bayhakki and Hatthakit (2012) explored themes related to the lived experience of haemodialysis patients. Four themes that emerged from the findings included 'having a physical shackle in life', 'feeling mental and emotional distress', 'relying on a haemodialysis machine', and 'dealing with problems'. The authors found that the experience of having a physical limitation can lead to a psychological burden which, if not successfully managed, can develop into mental and emotional distress that can influence physical health and physical activity over time. Bayhakki and Hatthakit also found that physical and mental problems can impact on patients' social life. Moreover, negative responses or views of others can negatively impact on patients, physically and mentally, including becoming a burden on patients and their families that can develop into emotional distress.

Another meta-synthesis by Siabani, Leeder, and Davidson (2013) explored the factors enabling and inhibiting self-care through studies of patients living with chronic heart failure (CHF). Findings indicated complexity in patients' ability to recognise symptoms, which had a negative impact on their ability to undertake appropriate self-care. Insufficient knowledge by patients about aspects of CHF was also a barrier to self-care as was environmental factors such as a problematic doctor-patient relationship. Moreover, misattributions (e.g. CHF attributed to stress) hindered self-care through non-adherence to medication. Conversely, a facilitator to self-care was social support which also enhanced CHF patients' mood. Psychological factors such as depression negatively impacted on self-care whereas self-care was unaffected by stress when using acceptance as a coping strategy.

The lived experience of chronic illness has also been studied in the context of identified processes for chronic illness self-management by Schulman-Green et al. (2012), which allowed the variability and complexity associated with the self-

management experience to be articulated. In this meta-synthesis, the authors identified three processes for chronic illness self-management: focussing on illness needs, activating resources, and living with a chronic illness. Focussing on illness needs was described as tasks and skills required for bodily care as well as attending to specific concerns associated with a chronic illness. Activating resources were individual and community resources and services required for optimum self-management. Finally, living with a chronic illness was related to coping and growth with chronic illness, including emotional processing, and transitioning from a focus on illness needs to integrating illness into everyday life. Schulman-Green et al. also found that self-management processes did not appear to be linear and often overlapped with each other. For example, a focus on emotional needs (living with a chronic illness) was sometimes required before focussing on illness needs. Based on Paterson's (2001) Shifting Perspective Model of chronic illness, outlined in Chapter 3, Schulman-Green et al. described living with a chronic illness in the context of illness self-management to be “a complex interaction between illness and life context” (p. 7).

One of the common chronic illnesses referred to in Chapter 3 was diabetes, which was also experienced by two of the participants (Spiro, Anthony) in the present study. Patients experiencing a chronic illness such as diabetes face multiple daily challenges in living with their illness, which can complicate their ability to self-manage their chronic illness (Schulman-Green et al., 2012). Previous studies (Uchenna, Ijeoma, Pauline, and Sylvester, 2010; Ahola and Groop, 2013), including Ingadottir and Halldorsdottir's (2008) study from an insider's perspective (Conrad, 1990) of the experience of illness self-management, are presented highlighting the complexity in patients' daily life with diabetes.

The lived experience of diabetic patients' adherence (or non-adherence) to a complicated treatment regime was explored by Ingadottir and Halldorsdottir (2008). Patients acknowledged their responsibility to manage diabetes and any complications, and intended to control their illness despite occasional failures. Difficulties were managed privately by many without seeking medical professional help, partly to avoid attention and also to maintain independence and to cope with shame, guilt, and frustration with poor management. Conscious decisions to raise blood glucose levels to avoid hypoglycaemia (low blood glucose level), without seeking help, were experienced alongside problems with hyperglycaemia (high blood glucose level) associated with dietary problems. Patients' attempts to find a balance and control of blood glucose levels were discordant with their health care providers' expectations. Patients also perceived the treatment regimen to be oppressive, but gradually adapted to it and learned to value it and attend to their diabetes and themselves.

A cross-sectional study by Uchenna, Ijeoma, Pauline, and Sylvester (2010) investigated patients' obstacles to their diabetes self-management. They found several psychosocial factors interfered with adherence to diabetes dietary regimen. These included frustration due to the restriction, limited social support, family conflicts, feelings of helplessness and inconvenience, irresistible temptations, difficulty in adhering in social encounters, and difficulty in revealing diabetes to the host of parties.

Ahola and Groop (2013) noted that the fear of hypoglycaemia (low blood glucose) can interfere with optimal diabetes self-management (self-monitoring of blood glucose levels), which can result from ineffective glucose regulation and lifestyle factors. If left untreated, hypoglycaemia can result in unconsciousness, convulsions, and possibly death. Individuals with diabetes will attempt to avoid



hypoglycaemia because of the negative symptoms, related health risks, and social influences. Fear of hypoglycaemia may also result in attempts to risk hyperglycaemia (high blood glucose) in order to avoid hypoglycaemia, which may be overcome with training in blood glucose awareness (Ahola & Groop, 2013). The next section will briefly discuss the role of context, in particular social and cultural influences, in shaping the subjective experience of chronic illness, and review studies in this area.

A study by Lu et al. (2012) exploring individuals' experience of living with chronic obstructive pulmonary disease (COPD) was also included because of its relevance to one of the participants (Michael) in the present study who also experienced a life event stress that appeared to profoundly impact his daily life with COPD. Lu et al. (2012) investigated the influence of life event stress on mental health and quality of life in elderly individuals with and without chronic obstructive pulmonary disease (COPD). They found both groups experienced symptoms of depression and a reduced quality of life relating to life event stress, but with a significantly stronger relationship for COPD individuals. Lu et al. suggested life event stress had a greater adverse effect on psychological wellbeing and quality of life in COPD individuals, possibly because of their perception and appraisal of stressful life events. Alternatively, COPD individuals' coping skills may have been inadequate or their social and economic resources may have been insufficient, or both.

### **Socio-Cultural Influences on the Illness Experience**

In order to aid our understanding of health and illness in any given society, human behaviour, social interactions, and societal structures must be explored within a cultural context. Culture is defined as the development of a shared body of knowledge and patterns of behaviour by a group of people who interact together (Sobo & Loustaunau, 2010). Culture also influences this group's way of living, values, beliefs,

method of communication, customs, habits, and preferences, as well as meeting society's needs through the allocation of power and authority, handling of goods and services, and religious practices. Moreover, culture governs the use of rituals, customs associated with day to day living, and recreation. Since culture infiltrates so much of a group's daily life within a society, it also influences a cultural group's perceptions and beliefs about health and illness and care-related decisions around health and illness (Sobo & Loustaunau, 2010). According to Kleinman, Eisenberg, and Good (1978), "Because illness experience is an intimate part of social systems of meaning and rules for behaviour, it is strongly influenced by culture: it is...culturally constructed" (p. 252).

It seems reasonable to acknowledge that the biomedical model's focus on disease, including the pathological effects on the body, has a rightful place in its goal of attempting to eliminate the symptoms relating to pathogen or disease. However, patients react to their diagnosis in ways that go beyond the symptoms of the disease at the time of their diagnosis. These reactions can be fuelled by cultural influences, such as cancer patients' reactions to perceived level of vulnerability, knowledge and beliefs about cancer, the attitude of others, level of trust in the doctor's competence, as well as the interruption to the patients' lives upon finding out about their cancer (Sobo & Loustaunau, 2010).

Cultural characteristics highlight the importance of context in symptom development in relation to disease, illness, and health. Therefore, whilst disease may originate within a biological sphere and develop through patterns of risk and exposure, these patterns are also socially and culturally influenced. Aging males' symptoms and diseases are experienced, understood, and interpreted within specific contexts, which suggests that an understanding and acknowledgement of their

perspective is required to help foster engagement on the matter of their health. It would therefore seem important to consider that, for all aging males, their health and wellbeing is based on the accumulation of a lifetime of experiences, with implications for their health (Consedine & Skamai, 2009).

Previous studies based on qualitative approaches have also developed insight into the influence of socio-cultural factors on the illness experience. For example, studies by Barbara and Krass (2013) and Krepia et al. (2011) have offered new insights into negative social influences on respective Maltese-Australian and Greek participants' adherence to their illness treatment regime, whilst studies, such as Avgoulas and Fanany (2012), have also provided insight into cultural influences on Greek-Australian participants' health behaviour. The lived experiences of these studies' participants with similar (i.e. Greek, Greek-Australian) and contrasting (i.e. Maltese-Australian) backgrounds to the Greek-speaking male participants in the present study were also included for purposes of comparison.

Barbara and Krass (2013) examined diabetes self-management issues in a Maltese-Australian community to help community pharmacies offer culturally appropriate support. Participants' knowledge of diabetes was generally limited, particularly in the elderly who were at risk of developing complications. Although participants understood and communicated in English, they appeared to lack education about diabetes. Adherence was primarily predicted by personal attitudes about treatment self-efficacy. Participants' perceptions and motivation, which were strongly influenced by peers, impacted on their self-management of blood glucose (SMBG). Peer experiences were valued above professional advice. However, interactions with non-diabetic peers negatively influenced medication adherence and dietary and physical activity recommendations. For instance, participants avoided

medication in the presence of non-diabetic peers, and chose foods similar to their non-diabetic peers and accepted hospitality to conform, which negatively influenced their dietary regimen adherence.

Krepia et al. (2011) investigated factors relating to elderly Greek participants' compliance with their hygiene and treatment regimen for their diabetes. Social factors were prevalent in dietary non-compliance. For instance, participants felt ashamed, and reluctant to explain their condition to others. They also felt deprived of foods enjoyed by others in their presence. Participants also experienced feelings of sadness, anxiety, and guilt with non-compliance of their treatment regimen. For some participants, tiredness and exhaustion led to dismay about their illness and their indifference to their doctors' instructions and eventual non-compliance with their treatment regime. On the other hand, constructive communication and encouragement between couples facilitated an environment which contributed to illness management. Compliance was also influenced by participants' personal will and self-knowledge. According to Krepia et al., participants may need psychological and social support to overcome their procrastination and transform their knowledge regarding their abilities into practice.

Avgoulas and Fanany (2012) explored the cultural and linguistic factors impacting on the experience of elderly Greek Australians' adaptation to cardiovascular disease (CVD) residing in a Greek aged care home. Participants believed that their diagnosis of CVD was related to God's will and attributed their state of health to fate and/or luck which had to be accepted and was outside of their control. In the Greek language, 'fate' and 'luck' have different connotations to those of the English language. The classical meaning of luck, or *τύχη* in Greek, referring to the control of the fortune of Greek city states by a minor deity, differed from the

contemporary meaning by indicating volition related to a higher being rather than random chance. Furthermore, fate, or *γὰρ* in Greek, refers to “something that is written” (Avgoulas & Fanany, 2012, p.85), and is commonly known in the Greek culture as “something that must happen to a person because it is predetermined and cannot not occur” (Avgoulas & Fanany, 2012, p.85). Adapting to illness for this population, particularly the elderly, meant accepting their illness as predestined, or determined in advance, by God, given the cultural belief that fate or luck is not random. Thus, these elderly Greek Australians had a tendency to believe that their illness (CVD) was an act of divine will rather than associated with any potentially avoidable risk factors. Furthermore, there was little incentive for them to change their behaviour because of the view that their illness was a result of fate. This group also viewed socialising within their cultural group to be more important than formal health care, with the former taking precedence over medical/health advice. Furthermore, participation in familial and communal social life was paramount. Having reached an advanced age, they felt it was their “responsibility to enjoy, accept, and use their time to the fullest” (Avgoulas & Fanany, 2012, p.85), such as participating in activities with children and grandchildren, engaging with church and religious community, and achieving personal happiness that they viewed as a gift from God. Instead of concern for their illness, they appeared more concerned about their illness preventing them from socialising with peers and family members. Religion was also important for this cultural group, which was a part of their cultural identity providing meaning to their illness and helping them cope with their stress and anxiety.

In summary, this chapter provided an outline of the limitations of the biomedical and biopsychosocial approaches to illness. The literature on patients’ experience of illness has also shown that this experience is different for each

individual. Thus, the experience of illness is subjective and idiosyncratic and holds meaning for the afflicted individuals, with beliefs and perceptions unique to their illness experience. These need to be acknowledged rather than overlooked in favour of objective and quantifiable approaches. The literature has also highlighted contextual (socio-cultural) factors that can influence the experience of chronic illness and which require consideration by health care professionals when working with individuals from different cultural backgrounds.

## **Chapter 3**

### **Chronic Illness**

This chapter presents literature on chronic physical illness. Unlike acute illness, which comprises symptoms having sudden onset and short-term duration, chronic illness lasts for a long time or indefinitely (Falvo, 2009; MedicineNet.com, 2007) and is defined in this study as illness which is present for three or more months (MedicineNet.com, 2007). According to Commonwealth of Australia (2014), several of the most common chronic illnesses in the elderly are asthma, arthritis, cancer, chronic kidney disease, chronic obstructive pulmonary disease, dementia, diabetes, osteoporosis, and stroke. In recent generations, the prevalence of chronic illness has increased, in part due to increased life expectancy. Based on the 2007-08 National Health Survey (NHS) (Australian Bureau of Statistics, 2010), 75% of the Australian population reported having a long-term medical condition. The increasing prevalence of chronic illness highlights a need to understand the lived experience of individuals with chronic illness, particularly for the elderly who may face increased chronic illnesses with complications and other co-morbidities. Sociologists, such as Bury (1982), Williams (2000), and Charmaz (1995b) have made an important contribution to understanding the complexity associated with individuals' lived experience of illness that included the interdependency between body, self, and society as well as the importance of considering timing, setting, and individual biographies (Lawton, 2003). Situations confronted by individuals in everyday life are often magnified for individuals with chronic illness (Charmaz, 2010). Challenges associated with “experiencing biographical disruptions, facing uncertainty, constructing selves and identities, being viewed as acceptable [e.g. stigma], and relating to others [including the doctor's influence on agency and self-management]” (Charmaz, 2010, p. 325)

raise unanswered sociological questions that require further exploration (Charmaz, 2010), particularly for non-English speakers who can be easily overlooked in an English-language focused science and literature. Moreover, the study of chronic illness experience can provide a rich opportunity to further advance sociological knowledge (Charmaz, 2010).

The present chapter begins with an outline of the differences between chronic and acute illness experiences. The chapter also briefly outlines a view that chronic illness was expected for individuals familiar with adversity or deprivation, as well as chronic illness viewed from different perspectives ('illness in the foreground' versus 'wellness in the foreground'). The experience of chronic illness in relation to its impact on the self and self-identity is also described. The chapter also discusses the benefits and pitfalls of non-disclosure and stigma for individuals with chronic illness. Finally, the issue of agency and the influence of the doctor-patient relationship on patients' management of their chronic illness are discussed, together with a review of studies from previous literature.

### **Chronic Versus Acute Experience of Illness**

Chronic illness differs from acute illness in important ways. An individual with an acute illness can change from a healthy individual to an individual who may take on the role of a sick person (Radley, 1994) for a relatively brief period of time and is often expected to make a relatively quick recovery (Falvo, 2009). For example, an individual may acquire a virus or flu and recover a few days later following rest and medication. In contrast, an individual with chronic illness can often experience a gradual change from a healthy condition to having to live with illness. Moreover, chronically ill individuals have to learn to cope with their condition whilst attempting to engage in everyday life and periodically require their doctors' services to address



symptoms related to their disease (Radley, 1994). Compared with an acute illness, the course and treatment of a chronic illness can vary. Chronic illnesses often commence in an abrupt and occasionally insidious manner and are characterised by a protracted and unpredictable course (Royer, 1998).

### **Chronic Illness: The Impact, the Self, and Identity**

The experience of chronic illness has been studied by psychologists, sociologists, nurses, and others. For example, illness viewed as a biographical disruption and the uncertainty of illness (Bury, 1982) which contrasts with illness within a life context (i.e. illness viewed as a part of life) (Pound, Gompertz, and Ebrahim, 1998; Williams, 2000) in sociology, the effect of illness on self-identity (Charmaz, 1991; Charmaz, 1995b) and on stigma and (non) disclosure (Goffman, 1986) in sociology, and coping and adaptation (Paterson, 2001) and ownership and agency with illness self-management (Koch, Jenkin, and Kralik, 2004) in nursing.

Bury's (1982) conceptualisation of the impact of chronic illness refers to a particular type of experience in which “the structures of everyday life and the forms of knowledge which underpin them are disrupted” (p. 169). According to Bury, individuals with chronic illness experience a significant interruption, or *biographical disruption*, in which taken-for-granted everyday experiences are disrupted and individuals are faced with the realisation of dealing with a longstanding disability rather than a temporary condition. Williams (2000), on the other hand, reported that crises associated with chronic illness were expected by individuals who had lived with adversity or material deprivation. Age can also mediate between the experience of chronic illness and response to chronic illness. For instance, Pound, Gompertz, and Ebrahim (1998) explored the lives of elderly individuals who experienced stroke. Ten months after their acute incident of stroke, their chronic illness did not appear to

create a major disruption to their lives. Most of these individuals reported that “things aren’t that bad” (p. 495) and downplayed the problems associated with stroke at the same time as mentioning the difficulties. This minimising of their stroke was interpreted as their way of coping with the event. Moreover, it appears that they had accepted their stroke with resignation and pragmatism which had become part of their lives. The authors attributed this to the elderly group’s confrontation with struggle and hardship throughout their lives, which also appeared to normalise their experience with stroke. According to Williams, it was “*timing and context, norms and expectations*, alongside our *commitment* to events, anticipated or otherwise” (p.51) that influenced individuals’ experiences, and the meanings attached to those experiences.

The Shifting Perspectives Model of chronic illness proposed by Paterson (2001) offered an alternative view regarding the impact of chronic illness. Paterson argued that people with chronic illness alternate or shift between periods in which their illness is the focus of attention (illness in the foreground) and periods where illness is less of a focus and the diseased body is kept at a distance. Focus, instead, turns to the self’s engagement in other aspects of life that are not presently consumed by the illness, such as relationships and the environment (wellness in the foreground). According to Paterson, this contrasts with models that depict illness as passing through stages (Livneh & Antonak, 1997) to reach an end goal. Although people with chronic illness may be experiencing wellness in the foreground, they may also need to pay attention to the requirements for treatment of their illness to try and keep illness in the background (Paterson, 2001).

Chronic illness has also been known to impact on individuals’ lives in other ways, such as altering their self-identity (Charmaz, 1995b). In particular, male

individuals' experience of chronic illness can threaten their identity, which can result in identity dilemmas, such as independent or dependent, public or private self, active or passive, autonomous or no control, and dominance or submission. Men's awareness that their illness is chronic can challenge their assumptions of competence, potency, and mastery that can also have an impact on their identity, as well as their psychological wellbeing. The uncertainty that can come with chronic illness can also lead to reappraisals of the self and self-reflection that can lead to important changes for men and their families (Charmaz, 1995b). Bury (1982) noted that individuals with chronic illness face challenges associated with a re-evaluation of the relationship between their sense of self and their illness, such as attempts to separate self from illness. Bury (1982) argued this was problematic given the tendency of illness to invade many aspects of individuals' lives. According to Charmaz (1995b), reconciling with chronic illness can assist individuals to preserve the self by inhibiting their illness from intruding on their lives. On the other hand, attempts to recapture the past self increases preoccupation with valued social and personal identities that are unattainable following chronic illness, which increases identity dilemmas. Difficult lifestyles or quality of life with chronic illness can disintegrate previous identities, whilst despair can increase following an inability to recapture the past self, making it difficult to preserve valued aspects of the self (Charmaz, 1995b). Furthermore, individuals with chronic illness who are isolated or absorbed in illness routines may feel that there is no life for them in the present and therefore locate themselves in the past (Charmaz, 1991). Thus, attempts to preserve the self, and discover valued identities with chronic illness, can be problematic when chronic illness symbolises lost former identities. On the other hand, the prospect of new identities can provide

motivation to resist disability and nurture hope, with self-preservation reflecting an emerging self that has the potential to develop positive identities (Charmaz, 1995b).

### **Non-Disclosure, Stigma, and Chronic Illness**

Chronically ill individuals have also attempted to limit the intrusion of chronic illness into their daily lives through non-disclosure or other attempts to hide their illness from others, with the aim of preserving the self (Charmaz, 1995b) and avoiding stigma. Attempts to engage in everyday life, such as social interactions and performing previously taken-for-granted tasks (e.g. work roles) by trying to fit in with others and hide illness, requires effort and becomes more difficult to maintain, which can result in withdrawal and social isolation (Bury, 1982). According to Goffman (1986), the term stigma is of Greek origin and refers to “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (p. 1). Individuals experiencing stigma who are discredited display visible signs of difference from others. Conversely, discreditable individuals can become discredited if information about their condition was disclosed to others (Goffman, 1986). Individuals who “pass for normal” (Joachim & Acorn, 2000, p. 245) deliberately attempt to conceal their condition to avoid being stigmatised and becoming discredited (Goffman, 1986). Moreover, avoiding disclosure about illness and concealing illness may allow individuals to adopt preferred identities that do not display illness. Disclosure may result in feelings of rejection and stigmatisation, inability to manage responses from others, emotional dysregulation, and loss of self-esteem or status, whilst concerns about receiving negative responses may also discourage disclosure (Charmaz, 1991).

A study by Joachim and Acorn (2003) provides an example of individuals’ decision-making process regarding disclosure of their chronic illness. According to

Joachim and Acorn's investigation of participants' experience with scleroderma, a progressive disease affecting skin and connective tissue (Farlex, 2013), participants with visible symptoms feared being stigmatised, discredited, and isolated. In contrast, participants with invisible symptoms made their own decision regarding illness disclosure. There was a general reluctance to disclose their illness to people, other than to close friends and relatives, to avoid special treatment (unwanted attention). According to Joachim and Acorn, participants risking non-disclosure had to manage the stress of concealing their illness, being discovered, and then being discredited (Goffman, 1986).

Chronically ill individuals' decision regarding disclosure can also extend to include family members, which can potentially impact on illness management and support. Patients with myocardial infarction hid their anxieties about their illness from family members (spouses), because they feared upsetting them (protective buffering) (Suls, Green, Rose, Lounsbury, & Gordon, 1997). According to Sulz et al. (1997), protective buffering may consume extra resources associated with managing relationships with family members beyond those required to manage illness. In addition, the patient may not receive appropriate social support.

### **Chronic illness: Agency, the Doctor-Patient Relationship, and Self-Management**

The intrusion of chronic illness may also challenge patients' beliefs about who (i.e. themselves or health care professionals) is required to assume responsibility for managing their chronic illness, related to the concepts of ownership and agency in chronic illness management. Agency in chronic illness refers to patients' abilities to take control of their own lives (Koch et al., 2004). Individuals' beliefs regarding the need for themselves or medical professionals to manage their illness are dependent, in part, on assuming ownership of their illness (agency). Psychological ownership of

illness can also be influenced by self-identity, and further shaped by psychosocial and cultural influences (Karnilowicz, 2010). Specifically, factors that may influence chronically ill individuals' ability to assume control of their illness include the patient-doctor relationship, culture, language, race, gender, and class (Tang & Anderson, 1999). With older people, the issue of agency in old age, and the connotations that come with it, creates a belief that the ageing process brings with it limitations imposed on the physical body, such as managing on one's own and maintaining an independent life. Consequently, this population can often attribute their health problems as an inevitable process of the physical body's degeneration which requires that they hand over control of their bodies, and other aspects of their lives, to others (Jolanki, 2009).

Traditionally, the biomedical model viewed chronic illness as a disease to be treated by the health professional, who is considered to be the expert responsible with finding solutions (Koch et al., 2004; Thorne, 1993). In the biomedical model of illness management, patients may have felt they had no alternative but to trust the medical profession who had the knowledge and ability to manage their illness. Medical management was imposed on patients rather than including patients in planning the management of their illness (Koch et al., 2004). In Thorne's (1993) study on patients' chronic illness experience, including the relationship between patient and health service provider, patients' trust and reliance on the provider without question meant that they viewed him as the person in control who knew what to do. Patients adhering to the medical model submitted complete trust in the health professional, viewed as a person with authority and a genuine interest in their wellbeing, with minimal (if any) contribution on their part in managing their illness. However, this risked creating resentment in patients when the doctor's instructions and advice did not fulfil their

expectations (Thorne, 1993). The type of information exchange between doctor and patient can also impact on patients' chronic illness experience. Parker and Adams (2008) examined the effect of information from medical professionals on patients following cardiac surgery. According to Parker and Adams, the type of information imparted to patients by their medical professionals can impact on their sense of self-efficacy as well as their mood. Patients may over-interpret medical advice (e.g. restraint from lifting becomes not moving at all), heightening patients' pessimism and inhibiting work resumption, and perhaps creating depression and anxiety. The authors contend that information and support to return to life pre-surgery would be more helpful, given the importance attributed to medical professionals by patients.

Patient characteristics, such as a willingness to become more active in the doctor-patient relationship, by asking questions and using their level of knowledge, can also impact on patients' ability to actively participate in the treatment process (Morgan, 2003). In a study of asthma self-management by Koch et al. (2004), some of the elderly people with asthma perceived self-management as other people managing their asthma. By assuming a passive role of non-participation in the management of their illness, patients may prefer to surrender the management of their illness to their doctors (patient role). Older patients' passivity in medical decision making with their general practitioners (GP's) was found in a qualitative study by Wrede-Sach et al. (2013). Patients preferred to engage in decisions concerning their daily lives, rather than decisions affecting their medical care, which they preferred to leave to their GP's. Cultural factors may also influence patient behaviour in the doctor-patient relationship. For instance, in a study by Almyroudi et al. (2011) of Greek patients with a life-threatening illness (breast cancer), patients' passive roles may have been influenced by their cultural context in which paternalism in decision making has been

dominant, with the potential for health care providers to view any attempt at active engagement negatively.

In summary, whether the arrival of chronic illness is experienced as a crisis that disrupts individuals' lives or an expectation as part of everyday life may depend on the timing of chronic illness and the context in which it occurs, which may also influence individuals' views regarding their chronic illness. Older individuals who may have experienced a life of adversity and hardship may adopt a pragmatic approach towards chronic illness as another event to be managed. The model by Paterson (2001) outlined individuals' perspectives of their chronic illness experience that alternate between periods in which there is a focus on illness (illness in the foreground) with periods where other aspects are the focus of attention (wellness in the foreground).

The literature also showed that the experience of chronic illness can result in changes to identity, with the disruption to previously taken-for-granted roles before chronic illness affecting the view of the self. By reconciling to their chronic illness, individuals may help to preserve the self and prevent the intrusion of chronic illness into their daily lives, which contrasts with a rejection of a reconciled self with chronic illness and attempting to recapture a pre-illness self-identity. Maintaining a preferred self-identity may also help individuals avoid stigma by concealing and not disclosing their chronic illness.

Assuming psychological ownership and responsibility for chronic illness (agency) can be influenced by old age, when individuals with chronic illness may prefer their doctors manage their illness. Individual characteristics and contextual factors (cultural, social) can also influence chronically ill individuals' participation (active or passive) with their doctors as well as the relationship between the doctor



and patient (authoritative or directive versus patient-centred or inclusive). Studies reviewing aspects of agency and the management of chronic illness in the context of the doctor-patient relationship were also presented in this chapter.

The concepts outlined in this chapter are also relevant, in general, to the experience of chronic illness in the present study and, in particular, to the Common Sense Model (CSM) of the self-regulation of health and illness (Leventhal et al., 2003) presented in Chapter 4. For instance, the impact of chronic illness on participants' illness experience may influence their perceptions about their chronic illness, such as the consequences and their ability to control their illness (CSM illness representations), and thus potentially influence their illness management (CSM coping procedures). Furthermore, the study's participants, who were all male, raises interesting questions regarding how they managed threats to the self and their identity in their experience with chronic illness, such as their identity within their social network, including their disclosure of illness and concerns about stigma. This may also influence their perceptions about themselves with chronic illness in social environments (social consequences [CSM illness representations]) with the potential to impact on their chronic illness management (CSM coping procedures). The issue of agency and taking responsibility for the management of chronic illness, particularly in the context of advanced age and the doctor-patient relationship, may also be related to the CSM. For instance, participants' views regarding their willingness (or not) to assume responsibility for their treatment (treatment control [CSM illness representation]) may potentially influence their passive or active engagement in both the doctor-patient relationship and the management of their illness (CSM coping procedure).

## **Chapter 4**

### **Self-Regulation of Health and Illness: Common Sense Model**

Chapter 2 outlined limitations to the biomedical and biopsychosocial approaches to illness, which fail to account for the subjective experience of illness that can also impact on health behaviour. Chapter 3 reviewed literature on several different approaches for understanding the impact of chronic illness on the lives of individuals. This included different perspectives about chronic illness (illness in the foreground versus illness in the background), the impact on the self and identity, stigma and non-disclosure with chronic illness, and agency regarding chronic illness management in the context of the doctor-patient relationship. These approaches can potentially influence individuals' illness perceptions, such as their views regarding illness consequences and control, potentially impacting on individuals' health and illness behaviours. These perceptions and behaviours are related to the Common Sense Model (CSM) of the self-regulation of health and illness (Leventhal et al., 2003), which is presented in this chapter. The CSM is dynamic in nature, forming a reciprocal relationship of cognitions (beliefs and perceptions) and affect with health and illness behaviours (coping methods) and appraisals. The CSM is also particularly suitable for individuals from different cultures given the influence of contextual (social, cultural) factors on cognitions and behaviour. Regarding cultural factors, for example, elderly Greek male individuals' beliefs that their chronic illness (cardiovascular disease) was determined in advance by an act of divine will (i.e. fate) (causal attribution) was related to their reluctance to engage in health behaviour change (Avgoulas & Fanany, 2012). In relation to social factors, for example, peers' experiences, which were valued above professional advice, influenced the perceptions and motivations of Maltese-Australian participants with diabetes, contributing to their

dietary non-adherence (Barbara & Krass, 2013). The inclusion of trial-and-error methods (heuristics), such as attributing illness to age (age-illness rule) (Leventhal & Crouch, 1997), makes the CSM also highly relevant for understanding the influence of age on cognitions and behaviour. The chapter also briefly outlines the importance of attending to distractions that can interfere with the pursuit of health-related goals and can lead to self-regulation failure. The potential influence of emotion regulation on other self-control aspects of illness is also discussed.

### **The Common Sense Model (CSM) of the Self-Regulation of Health and Illness**

The Common Sense Model (CSM) of the self-regulation of health and illness (Leventhal et al., 2003) is a theoretical framework that describes a self-regulatory parallel process model representing the layperson's process of dealing with health threats. It assumes that the illness is processed at both a cognitive and an affective level. The theory evolved from early work on fear communications, examining people's beliefs and reactions to fear related information, which led to inconsistent findings that enduring behaviour and attitudinal change is driven by fear reduction (Leventhal et al., 1997). This led to a parallel processing model of health threats comprising of a cognitive and an affective level (Leventhal, 1970) that evolved to become the CSM, as shown in Figure 1.

According to Leventhal, Leventhal, and Cameron (2001), the CSM has several advantages over other models of health behaviour, such as the Health Belief Model (Abraham & Sheeran, 2007) and the Theory of Planned Behaviour (Sutton, 2007). The Health Belief Model refers to beliefs in “the likelihood of experiencing a health problem, the severity of the consequences of that problem, the perceived benefits of any particular health behaviour and its potential costs” (Abraham & Sheeran, 2007, p. 97) which guide health behaviour. Moreover, the Theory of Planned

Behaviour is a model in which “behaviour is determined by the strength of the person’s intention to perform that behaviour and the amount of actual control that the person has over performing the behaviour” (Sutton, 2007, p. 223).

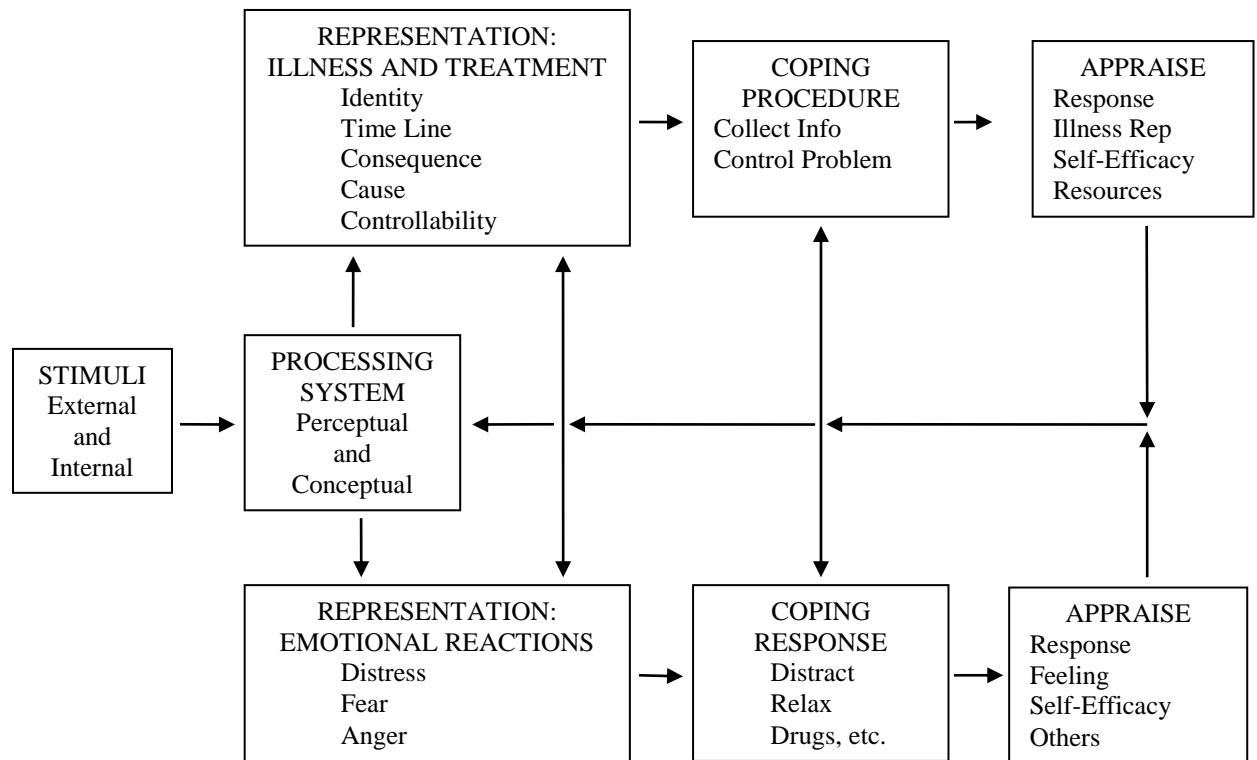


Figure 1. Commonsense model of illness. From *Aging, Health, and Behavior* (p. 112), by M. G. Ory, R. P. Abeles, and P. D. Lipman, 1992, Newbury Park, California: Sage Publications. Copyright 1992 by Sage Publications. Reprinted with permission.

The CSM’s advantages over the abovementioned models are as follows:

First, the CSM includes a focus on cognitive representations and emotional responses

rather than sources of motivation based on attitudes or vulnerability. Second, the inclusion of abstract and concrete illness representations and emotional reactions allows for the possibility of different goals and outcomes. Third, the inclusion of process allows for procedures as well as expectations and appraisals to be revised in line with changes in illness representations based on the 'if-then' rules that relate illness representations to coping procedures (Leventhal et al., 2001). For example, if individuals have a headache, then taking medication would be expected to cure the headache in about one hour, or if individuals experience breathlessness which persisted, then they may seek medical help. These 'if-then' rules reflect a self-regulation system that is considered to be complete and coherent once the illness representations have been linked to coping procedures and action plans (Horowitz, Rein, & Leventhal, 2004).

### **CSM Assumptions**

Leventhal and Nerenz (1985) outlined several assumptions that underpin the common sense model:

1. Individuals become actively involved in solving problems rather than passively responding to their environment. Their perceptions and appraisals of stimuli are related to their behaviour. Individuals' perceptions and representations are derived from the combination of their environment and knowledge and past experience (memory schemas), which are based on cognitive and emotional aspects.
2. With the exception of the output (behaviour, action, speech), many of the cognitive processes, including the knowledge base that forms the basis for the CSM, are not observable.

3. The generation and response to specific illness problems is time-limited, with the process of construction and refinement of illness representations comprising of a start and an end.
4. Illness representations are influenced by both situational and individual factors. Variation in common sense models is influenced by individual variation and unique circumstances, which complicates the ability to predict outcomes.

### **The Dynamic Nature of the CSM**

The dynamic self-regulatory process of the CSM is based on a control system framework known as the TOTE (test, operate, test, exit) system, which is a self-regulatory process only (no content) system that detects and evaluates disturbances (compares a reference signal to an input and generates an output function [equivalent to behaviour] to reduce any discrepancy between the reference signal and input [Carver & Scheier, 1998]). However, the control system associated with the CSM extends beyond that of the TOTE system by defining the characteristics of each of the elements within the system, such as self-regulatory content and process (Leventhal et al., 2003). With the CSM, health threats are processed as incoming stimuli (internal, external). The cognitive component, one path of the model (danger control), describes the cognitive representations related to the health threats and the corresponding procedures put in place to manage the threats. The affective component, a second parallel path of the model (fear control), describes emotions of fear and distress generated by the health threats and the procedures adopted to manage the generated emotions. The individual's appraisal of the efficacy associated with the actions to reduce the health threats, as well as the negative emotions generated by the threats, will determine the extent to which corrections are required to the individual's

representations of the stimuli (Leventhal et al., 2003). The CSM shares features in common with other self-regulatory models (Carver & Scheier, 1998; Miller & Diefenbach, 1998). However, it also differs from other models in that representations of health threats are separate from the procedures to manage the threats (Leventhal et al., 2001).

### **Illness Representations: Content, Heuristics, and the Influence of the Self and the Social Environment**

Illness representations are individuals' perceptions of health threats based on knowledge and experience. The content of illness representations are used to form goals and develop coping procedures and action plans for attaining goals and appraising outcomes (Leventhal et al., 2001). The interpretations of health threats utilise a number of dimensions (Scharloo & Kaptein, 1997), which are illustrated using the example of myocardial infarction. Individuals' perceived identity of the problem refers to the diagnostic label (heart attack) and symptoms (breathlessness, chest pain) related to their illness. Views about the cause of illness can be attributed as either internal (lack of exercise) or external (heredity) to the individual. Individuals' perceptions of potential consequences of their illness include short-term and long-term effects of their illness, which are typically categorised according to physical (reduced mobility), psychological (depression), and social consequences (stigma). The timeline dimension refers to participants' views regarding the duration of their illness (acute or chronic) and course (episodic/cyclical, continuous, expected to worsen/improve/stay the same). The dimension of cure/controllability refers to participants' views regarding cure and their ability to control their illness (Scharloo & Kaptein, 1997).

Illness representations are processed using both bottom-up (concrete) and top-down (abstract) levels. For instance, the ill person defines the symptoms in concrete terms (increased heart rate) and the abstract label for the symptoms (stress) (Leventhal, Nerenz, & Steele, 1984; Martin, Rothrock, Leventhal, & Leventhal, 2003). Illness representations can also develop an expectation for the perception of symptoms in specific situations (Martin et al., 2003). The process by which stimuli, both internal and external, make the transformation into representations includes the use of heuristics, or mental rules of thumb, which provide a simple, quick, and efficient evaluation of symptoms. With this type of cognitive processing, the symptoms associated with the health threat are often attributed to other factors, such as age or stress, rather than symptoms of the illness (Leventhal, Halm, Horowitz, Leventhal, & Ozakinci, 2004; Martin et al., 2003). Ongoing interpretations made about the stimuli related to an illness and the associated procedures used to control the illness threat often use heuristics, which help develop a more comprehensive picture of the representation of the illness threat over time. Representations undergo transformations in accordance with the success or failure associated with the procedures to modify the disease process. The way an individual makes sense of these repeated modifications will influence the heuristic used to evaluate the implications (Leventhal et al., 2003).

Symptoms attributable to their location rather than their source are referred to as a locational heuristic, such as individuals with chronic heart failure who attribute their breathlessness to the lungs instead of the heart (Leventhal et al., 2004).

According to Leventhal and Crouch (1997), age can influence the representation of an illness threat, the corresponding coping procedures to manage the threat, and appraisal of the threat. The authors argue that symptoms developing with



old age must be evaluated against a background of bodily changes occurring with age, given the co-occurrence of chronic conditions with age-related biological changes. Moreover, the detection of symptoms becomes more difficult with age because of their attenuated presentation with increasing age. Age-related consequences may complicate differentiation of symptoms attributable to the illness from those attributed to aging, potentially leading to increased morbidity and mortality in the absence of professional medical help (Leventhal & Crouch, 1997). Prohaska, Keller, Leventhal, and Leventhal (1987) examined symptom attribution to aging (age-illness heuristic) and the effect on coping procedures. Older participants tended to attribute their symptoms to ageing. Symptoms that were brief, severe, and not attributed to ageing were more likely to result in negative emotional expression and the activation of coping procedures, such as contacting the doctor or accessing the emergency room. Conversely, symptoms attributed to ageing and not related to symptom severity resulted in acceptance of symptoms and a delay in presenting symptoms to the doctor. Thus, redirecting symptom attribution of illness to ageing may affect initiation of appropriate coping procedures (Prohaska et al., 1987).

Conserving energy avoids the effort of evaluating ambiguous symptoms, which can influence health-related behaviours (conservation heuristic). Instead of drawing on their own limited resources, older people with illness may place their trust in their health care providers to assume responsibility for evaluating and making decisions on their behalf regarding their symptoms (Martin et al., 2003). Energy conservation can also impact on illness perceptions and behaviour. For example, cardiac patients are inclined to conserve energy if they believe that strenuous physical activity or emotion will result in a heart condition, such as myocardial infarction (Martin et al., 2003). Older individuals have also sought medical help faster than their

middle-aged counterparts, suggesting that individuals are prone to engage in resource conservation and aversion to risk with age (Leventhal, Easterling, Leventhal, & Cameron, 1995).

Illness representations can also be influenced by self-identity and the social environment (Brownlee et al., 1999). An individual's characteristics in relation to self and identity may influence illness representations, conflicting with and altering representations of the self (Leventhal, Idler, & Leventhal, 1999). Bottom up processes, such as changing symptoms or a deterioration in functioning, can lead to questions related to the self and identity, for example, 'who am I?'; 'what will I become?'; 'will I function as a person?' Top-down processes, such as beliefs and expectations of illness consequences, will be influenced in part by views of the pre-illness self and affectively laden views of self and identity in line with changing illness representations. Furthermore, the influence of the social environment (family, friends, doctor, and media) on illness representations, coping procedures, outcomes, and efficacy, can also influence top-down processes to affect changes (either positive or negative) to self and identity (Leventhal et al., 1999). Regulating self-identity with changing illness representations would likely indicate successful adjustment (Brownlee et al., 1999).

### **Coping Procedures and Appraisals**

Selection of coping procedures and action plans to remove or manage existing or potential illness threats are shaped by illness representations (Leventhal et al., 2003). Furthermore, appraisal of coping procedure outcomes can also reciprocally influence illness representations. Based on the common-sense nature of illness representations, the procedures selected to cope with a particular illness are perceived to be appropriate and required, and therefore psychologically correct despite their

possible irrelevance in controlling or curing the condition (Leventhal, Diefenbach, & Leventhal, 1992). Dimensions for coping procedures are similar to the dimensions of illness representations and are based on abstract and concrete, or experiential, features. For example, patients taking medication could expect to feel better after a week (expected component), when in actual fact it may take two weeks (actual component), and they may feel like it's taking ages for them to feel better (experiential component) (Brownlee et al., 1999).

The stress coping model by Lazarus and Folkman (1984) refers to an individual's appraisal of the extent of threat imposed by a stressful situation, and the available resources to manage the threat. According to this model, an individual's reaction to the threat comprises problem-focussed and emotion focussed coping styles. Problem-focussed coping refers to coping by managing or modifying a stress-related problem appraised as changeable. Conversely, emotion-focussed coping refers to coping by regulating one's emotions in response to a stress-related problem appraised to be unchangeable. Important distinctions have been made between the coping procedures used to cope with a health threat (Lazarus & Folkman, 1984) and coping with illness as applied to the CSM (Leventhal et al., 1997; Leventhal et al., 2001). Coping procedures tend to be performed automatically and therefore independent of any conscious deliberation (Leventhal et al., 2001). Coping is viewed by lay individuals as a goal directed activity with a positive valence. However, there is no special virtue attached to the term 'procedure' for the prevention or control of illness (Leventhal et al., 1997). Studies on chronic illness that relate CSM illness representations with coping behaviour (both adaptive and maladaptive) and outcomes (both positive and negative) are reviewed in the next section.

## **Patients' Experience of Chronic Illness and the CSM**

According to Weiner's (1986) theory, causal attributions comprise of three dimensions: stability (changeability of cause over time), locus of causality (internal or external), and controllability (causes that are [or not] under one's control). Individuals with chronic illness displaying unstable, internal, and controllable causal attributions tended to use approach forms of coping (motivating cognitions and behaviour) and displayed better adjustment than individuals with stable, external, and uncontrollable causal attributions, exhibiting avoidant forms of coping (helplessness and resignation) and poorer adjustment (Roesch & Weiner, 2001). Moreover, patients undergoing thoracic surgery viewed their physical condition as a bodily-related problem, implying external imposition of disease on their bodies (external attribution), over which they had no control (DuCette & Keane, 1984).

Wearden, Hynd, Smith, Davies, and Tarrier (2006) investigated whether spontaneously elicited casual attributions of blood glucose control (spontaneous causal attributions) were associated with blood glucose control, self-management, and diabetes adjustment in adult patients. Personally-relevant or idiosyncratic spontaneous causal attributions were associated with blood glucose events and dysfunctional blood glucose control with problematic self-management behaviour mediating between personal causal attributions and increased blood glucose levels. According to Wearden et al., patients attributing blood glucose events to personally-relevant factors were less likely to attempt to change their behaviour, even if they perceived these factors to be potentially controllable, because they viewed the causes as part of their own make-up or habitual behaviour.

According to Hirani and Newman (2005), who explored the types of cognitions and beliefs that patients with cardiac-related conditions have about their

illness, patients who do not view bodily sensations such as tightness in the chest to be a serious condition may delay seeking help. On the other hand, patients' over-emphasis on bodily sensations may interpret them to be a cardiac condition leading to increased heart-related anxiety and cardiac invalidism. They may also assume a passive and helpless position, believing that overexertion could lead to myocardial infarction. In addition, cardiac patients' beliefs may influence their health behaviour. For example, if they believe their condition is not chronic or does not have serious consequences, they may not take action. Beliefs about self-efficacy and personal control may also influence patients' ability to engage in appropriate health behaviours.

Aljaseem, Peyrot, Wissow, and Rubin (2001) examined the relationships of treatment barriers for diabetes and self-efficacy with self-care behaviours for adult patients with type 1 diabetes. Findings showed that patients who felt confident about implementing the planned tasks tended to test their blood glucose more frequently, adhere to an appropriate diet, and reduce their binge eating. Patients who felt that they could perform insulin tasks were also more frequently adjusting their insulin to prevent hyperglycaemia (high blood glucose). Furthermore, treatment efficacy was found to be important when treatment barriers were high, highlighting the importance of self-efficacy during challenging tasks to overcome obstacles interfering with the treatment regimen.

Chilcot, Wellsted, and Farrington's (2010) findings highlighted the importance of CSM illness representations in guiding fluid adherence in end-stage renal disease (ESRD) patients. Patients were more likely not to adhere to fluid intake requirements if they perceived themselves to have lower serious consequences than their fluid-adherent counterparts.

The ability of the CSM to predict self-care behaviour regarding diet, fluid, and medication adherence in patients with end-stage kidney disease (ESKD) was assessed by O'Connor, Jardine, and Millar (2008). Illness representations were found to predict self-care behaviours, but not fluid adherence, over and above clinical and medical factors with emotional and timeline representations predicting dietary and medication adherence. Coping strategies did not mediate the relationship between illness representations and self-care behaviour, which was attributed to inadequate coping measures and perhaps patients' difficulty in identifying habitual coping responses. Moreover, emotion-focussed coping predicted variation in fluid adherence, which may be related to ESKD individuals' coping techniques (positive re-appraisal, humour) as an occasional temporary distraction from fluid adherence.

A study by Tasmoc, Hogas, and Covic (2013) examined changes in illness perceptions at follow-up compared with baseline for haemodialysis patients over time (6 year period). Perceptions of personal control and a cyclical timeline remained unchanged, but perceptions of treatment control and illness coherence increased. This suggests that patients believed they had better control over illness treatment requirements (treatment control) and improved understanding of their illness (coherence). Perceptions of treatment control were also associated with mortality, after controlling for socio-demographic factors. Emotional representations reduced in intensity, suggesting that patients were less emotionally affected by their illness. Patients' beliefs about illness consequences also reduced, suggesting that consequences were less serious than at baseline. Overall, the findings indicated that patients' perceptions of their illness improved over time.

A longitudinal qualitative study by Peel, Douglas, and Lawton (2007) explored lay beliefs of patients with type 2 diabetes regarding self-monitoring of their

blood glucose levels. Patients reported advantages of self-monitoring, such as objective readings increasing their awareness and responsibility for their illness, and providing satisfaction in maintaining levels within the required limits. However, some patients also reported numerous disadvantages with self-monitoring. For example, an obsession with monitoring, obtaining counterintuitive glucose readings and uncertainty about the reasons for high glucose readings, which created anxiety and distress, and increased responsibility leading to self-blame and negative emotional reaction to elevated blood glucose readings. Thus, well controlled diabetes provided positive views of self-monitoring whereas poorly controlled diabetes increased self-monitoring concerns and problems for patients.

Paraskevi (2011) also explored differences between health beliefs for elderly Greek end-stage renal disease patients on haemodialysis (HD) and peritoneal dialysis (PD), and any association between patients' health beliefs and health-related quality of life (QoL) and mental health. There was a significantly higher internal health locus of control in HD patients, indicating that they regulated their condition based on their personal control which may have helped compensate for the increased dependency on their treatment (haemodialysis) and dietary regimens. For all patients, it appears that an internal locus of control was related to better psychological health and overall QoL/health with fewer somatic symptoms, whilst control and responsibility for patients' illness by important others was related to increased depression.

According to Cohen, Janicki-Deverts, and Miller (2007), external (environmental) stressors, which can include stressful life events, may facilitate a path to disease which is mediated by behavioural responses adopted by individuals to cope or adapt to the stressors, such as smoking, reduced physical activity, insufficient sleep, and not adhering to the medical regimen. Myocardial infarction (MI) patients'

beliefs about their stress, including its functioning, and the relationship with MI were examined by Clark (2003). Findings indicated that participants perceived stress to be a common cause of heart problems rather than a consequence of MI. Stress was perceived by participants to be more influential than other risk factors, such as smoking and diet, and the primary cause of coronary heart disease (CHD) which needed to be avoided because of their perception that it could re-trigger another MI.

A meta-analytic review by Hagger and Orbell (2003) found relationships between CSM illness representations and coping procedures. Beliefs in serious consequences and a strong illness identity were positively related to avoidance/denial and the expression of emotions. Beliefs in cure/control and cognitive reappraisal were positively related to problem focussed coping and seeking social support. CSM illness representations were also related to outcomes. Beliefs in serious consequences, a strong illness identity, and a chronic timeline were negatively related to psychological wellbeing, social and role functioning, and vitality (helpful outcomes), and positively related to psychological distress (unhelpful outcome). Illness controllability was also positively related to psychological wellbeing and vitality. The results provided support for *a-priori* hypothesised relationships between illness beliefs, coping procedures and outcomes across studies.

Rutter and Rutter (2002) also examined inter-relationships between illness representations (IRs), whether IR's predicted coping strategies, and whether coping played a mediating role between IR's and outcome for adult patients with irritable bowel syndrome (IBS). IR's appeared to be related to each other, to coping strategies, and to illness outcomes. Coping was also found to mediate relationships between IR's and illness outcomes. However, direct relationships between IR's and outcomes were



also found. A limitation of the study was no exploration of an emotional representation path of the common sense model.

The CSM (Leventhal et al., 2003) assumes that individuals are motivated to become actively involved in responding to health threats. However, the CSM's focus on illness representations appears to have overshadowed the role of coping regarding individuals' ability to remain focussed on goal pursuit in order to prevent self-regulation failure (De Ridder & De Wit, 2006; Sheeran, Webb, & Gollwitzer, 2006), as well as individuals' focus on emotion regulation at the expense of other goal pursuits, such as behavioural self-control (Tice & Bratslavsky, 2000).

### **Self-Regulation Failure**

According to Baumeister and Heatherton (1996), self-regulation failure occurs when individuals are unable to modify their responses, through their own volition or self-control, to overcome the influence of concrete environmental stimuli that can interfere with their pursuit of long term goals. Baumeister and Heatherton attribute self-regulatory failure to a strength model of self-regulation. According to this model, individuals' insufficient capacity (strength) to overcome uninvited cognitions, emotions, or impulses, results from exhaustion (depletion of energy) associated with multiple competing demands interfering with their self-control efforts. However, Martijn, Alberts, and de Vries (2006) argued that individuals' expectations of limited self-controlling capacities, rather than their actual capacities, contributed to their self-control outcomes. Thus, positive control 'mindsets' (expectancies) appear to override individuals' depleted resources (energy levels) to maintain self-control of their illness (Martijn et al., 2006).

According to De Ridder and Kuijer (2006), individuals' attempts to ignore their frustrations and distractions interfere with the pursuit of goals, including health-

related goals. Problems with goal attainment and behavioural performance, such as failing to initiate goal pursuit or maintain goal pursuit once started, may also arise (Sheeran et al., 2006). According to Sheeran et al. (2006), the initial reluctance to act can run into self-regulatory problems when a goal intention is faced with a reality that threatens that goal. For example, diabetic individuals' intention of reducing their consumption of biscuits may be threatened by the presence of biscuits presented in front of them in a social context (e.g. Greek hospitality).

### **Emotion Regulation**

Emotion regulation refers to the replacement of an emotional expression or emotional experience with an incompatible emotional expression or experience. For instance, using relaxation to regulate feelings of anxiety or anger, or substituting sad thoughts with more pleasant thoughts to overcome depression (Tice & Bratslavsky, 2000). According to Tice and Bratslavsky (2000), a relationship exists between self-control and emotion. Difficulty with self-control can result from negative emotional states when individuals' efforts are particularly focussed on regulating their negative moods in order to overcome their emotional distress. However, by focussing on regulating their emotions, individuals can forgo other self-control goals which can lead to self-control failure. For example, chronically ill individuals with diabetes or end-stage kidney disease may succumb to temptations for sweets or abandon restrictions to food and fluid intake when they are preoccupied with regulating their anxiety. Thus, emotion regulation may be particularly influential for self-control because of the importance placed on it ahead of other self-control behaviours and the potential negative impact on other self-control efforts (Tice & Bratslavsky, 2000).

In summary, the CSM is an appropriate theoretical framework for conceptualising the experience of individuals with chronic illness, which also

incorporates individual, social, and cultural influences that can impact on their experience. In particular, the CSM allows for an exploration of individuals' perceptions (illness representations) and emotional responses to chronic illness which can guide their behaviour (coping procedures) and their appraisal of outcomes. The reciprocal interplay between illness representations, coping procedures, and appraisals is a dynamic process aimed at the self-regulation of a health threat. Furthermore, the characteristics of individuals with chronic illness in relation to the self and identity are integral with illness representations whereby they impact on and are impacted upon by illness representations with the potential to influence their coping procedures and outcomes. Other influences can also interfere with the CSM's illness representations, such as heuristics (mental 'rules of thumb'), which can lead individuals to attribute their illness to other factors (age, stress) and potentially modify their behaviour, such as seeking medical help, which is particularly relevant for the elderly including the participants in this study. Information gained from the CSM's use may potentially contribute to the practical development of appropriate treatment interventions for individuals with chronic illness, including the elderly and individuals from different cultural backgrounds.

Individuals' self-regulation of their chronic illness may, at times, be threatened by obstacles that interfere with their self-regulation and can potentially lead to self-regulation failure. Short-term frustrations and distractions, such as temptations (e.g. sugary foods), can interfere with the pursuit of long-term goals (e.g. adherence to dietary treatment regime). Problems with self-regulation can also occur when a goal intention is confronted with a reality that threatens goal pursuit, such as the presence of contextual (sociocultural) influences. The literature has also shown that negative self-control outcomes may be related to individuals' expectations of

limited self-control capacities. Individuals focussed on regulating their emotions may also forgo other self-control tasks contributing to self-regulation failure.

## **Chapter 5**

### **Chronic Illness: Psychosocial Adjustment and Social Influences**

This chapter describes psychosocial adjustment to chronic illness based on a conceptual model of adjustment by Sharpe and Curran (2006) and outlines the processes that can lead to either positive or negative outcomes. The model of adjustment to chronic illness is particularly useful for understanding how individuals are able (or not able) to establish adaptive views of the self and the world when faced with persistent challenges in their experience with chronic illness. Several key processes of psychological adjustment (search for meaning, response shift) are described and a model of response shift (Sprangers & Schwartz, 1999) is presented that outlines how individuals are able to maintain a quality of life despite adversity, such as chronic illness. Studies on the benefits arising from chronic illness, including an optimistic orientation, are also reviewed. The chapter also outlines the use of social comparison as a method of coping in relation to the Common Sense Model (CSM) of the self-regulation of health and illness (Leventhal et al., 2003), and its influence on the mental health and wellbeing for individuals with chronic illness. A conceptual model by Heany and Israel (2008) is also presented, which outlines the relationship of social support and social networks to health. The influence of social support and social interaction (companionship) on positive and negative health outcomes are also outlined, along with the influence of perceptions of dependence or independence on the role of social support. Studies reviewing the influence of social support and social interaction are also presented in this chapter.

#### **The Process of Adjustment to Chronic Illness**

As outlined in Chapter 4, illness representations related to the CSM are developed in the face of a health threat (Leventhal et al., 2003) and based on pre-

existing belief structures (schemas) (Leventhal & Nerenz, 1985). Models such as the CSM have emphasised the importance of establishing concordance between the belief-based illness representations and the reality of a situation (Sharpe & Curran, 2006). According to Sharpe and Curran (2006), adjustment is the process of preserving a positive view of the self and the world in the presence of a health problem, such as chronic illness. A conceptual model of adjustment to chronic illness proposed by Sharpe and Curran is shown in Figure 2. Optimistic individuals or individuals with a promising prognosis of illness are likely to develop helpful illness representations which, if accurate, can translate into adaptive psychological functioning. However, unhelpful illness representations may also result, stemming from past experience, individual characteristics, or when illness or its consequences are severe. In the absence of helpful illness representations, individuals will try and re-establish equilibrium by creating more adaptive views of their illness. For example, individuals may alter the meaning of an event (situational meaning) (Park & Folkman, 1997) such as chronic illness. If their efforts are unsuccessful, other approaches may be adopted to try and restore equilibrium, such as questioning the 'if-then' rules (Leventhal et al., 2001) that influence coping behaviour. If emotional equilibrium cannot be achieved, individuals may attempt to change beliefs about the world and re-prioritise values and goals (response shift) (Sprangers & Schwartz, 1999) to re-establish equilibrium and facilitate illness adaptation. Thereafter, individuals may attempt to change the meaning of their illness experience as part of their self-identity, such as identifying inner strength in their attempts to manage the health threat (Charmaz, 1995b). Alternatively, goals and priorities that previously provided meaning in life may be reconsidered as part of a search for meaning in order to restore emotional equilibrium, particularly when individuals' values and beliefs are

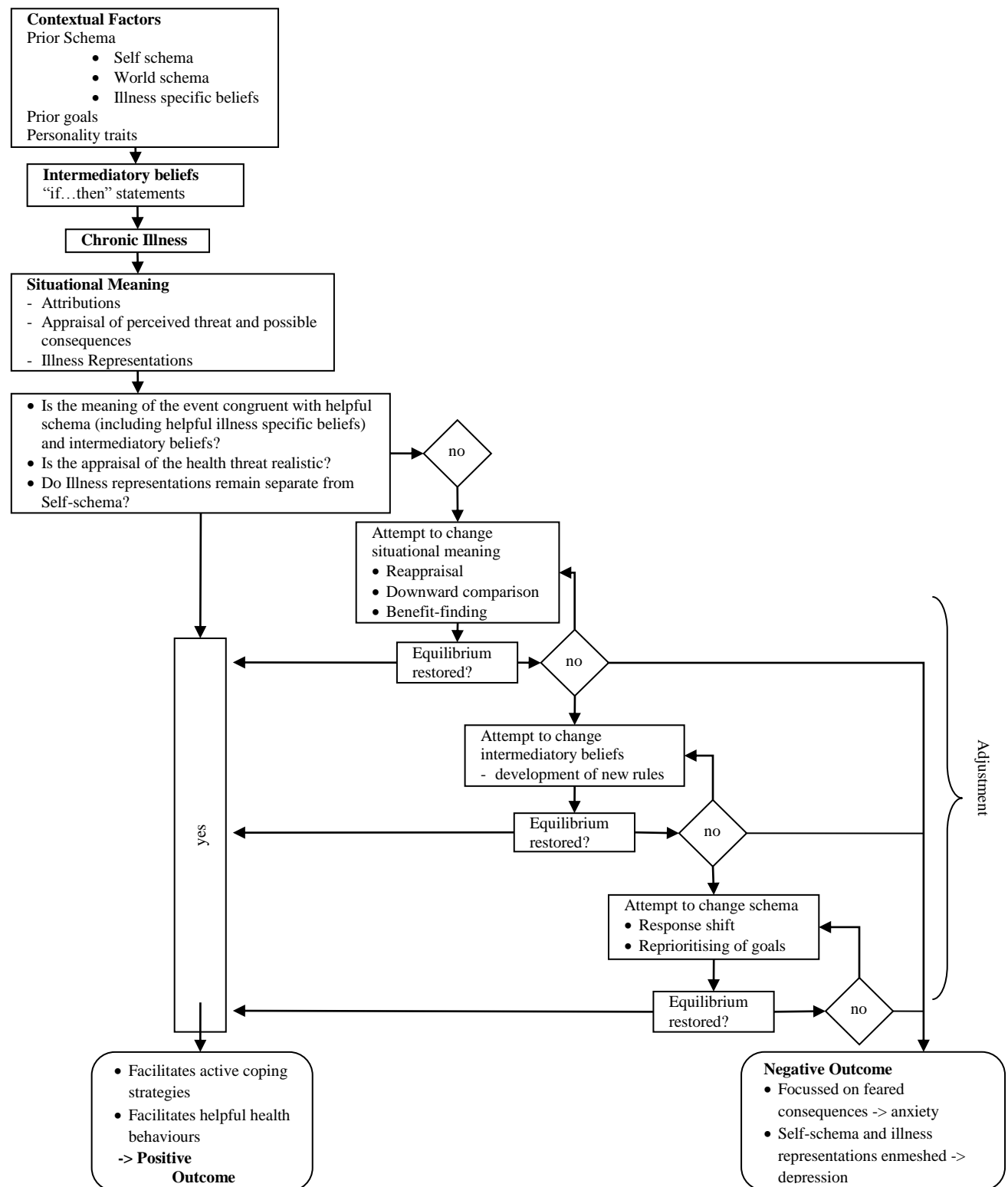


Figure 2. A model of adjustment to chronic illness. From “Understanding the Process of Adjustment to Illness,” by L. Sharpe and L. Curran, 2006, *Social Science & Medicine*, 62, p. 1162. Copyright 2005 by Elsevier Ltd. Reprinted with permission.

threatened. In the event that more helpful views of illness are not forthcoming, or if any process is unresolvable, then maladjustment or psychopathology may ensue (Sharpe & Curran, 2006).

### **Searching for Meaning in Chronic Illness**

There are different approaches in the adjustment to adversity, such as chronic illness, that contribute to an understanding of individuals' attempts (or not) to achieve emotional equilibrium, which may result in either positive or negative outcomes. One approach relates to a search for meaning (Park & Folkman, 1997, Skaggs & Barron, 2006), with the aim of seeking order and purpose in life despite chronic illness. According to Skaggs and Barron's (2006), global meaning is "a person's generalized meaning in life pertaining to their purpose/goals, values, and beliefs about what is important, and a sense that life is understandable and predictable" (p. 562). Order and purpose are two dimensions of global meaning. Order refers to beliefs about the world, the self, and the self in the world, such as viewing life and oneself in it as predictable, whilst a sense of purpose is striving for goals, which has also been predictive of general life adjustment (Park & Folkman, 1997). In contrast, situational meaning is "the interaction of a person's global beliefs and goals and the circumstances of a particular person-environment transaction" (Park & Folkman, 1997, p. 121), which comprises of three components, namely appraisal of the situation (event), a search for meaning, and meaning as outcome.

A search for meaning ensues following individuals' appraisal of a situation if they perceive a negative outcome to an unforeseen event and themselves as having insufficient resources to cope with the event or their resources are discordant with global meaning (Skaggs & Barron, 2006). Finding meaning in a negative event, such as chronic illness, may help individuals reduce any discrepancy between global

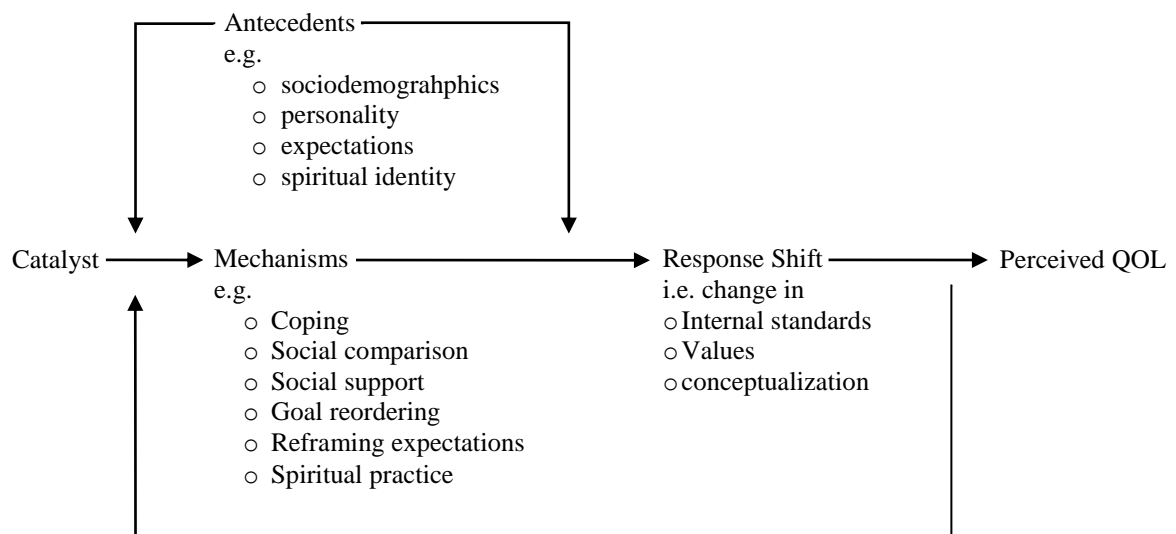


meaning and situational meaning to re-establish emotional equilibrium. To achieve congruence between situational and global meaning, individuals may attempt to change the situational meaning of a stressful event such as chronic illness through re-attributions and creating illusions. For instance, when inflated, the illusion of personal control may help individuals adapt to unexpected negative events (Sommer, Baumeister, & Stillman, 2012), such as altering their behaviour by adopting inflexible lifestyle changes with illness onset to alter the impact of the event on their lives (Janoff-Bulman & Frantz, 1997). Individuals may also view themselves to be better than others, including engaging in downward social comparisons (Wills, 1981). Conversely, loss or a negative event, with consequences not easily ameliorated through coping processes to change the situation, may not be easily integrated into individuals' existing beliefs, requiring the alteration of their fundamental beliefs or goals to change global meaning (Park & Folkman, 1997). This may involve re-evaluating the value of ordinary events to increase their importance, such as appreciating and enjoying taken-for-granted events, generating positive events, or being grateful for each day and taking one day at a time (Skaggs & Barron, 2006). Individuals unable to establish congruence between situational meaning and global meaning may face adjustment difficulties (Park & Folkman, 1997, Skaggs, 2006 #374), such as depression or loss of purpose.

### **Response Shift With Chronic Illness**

Another approach that has been related to adjustment to chronic illness, response shift (Sprangers & Schwartz, 1999), has enabled individuals to maintain a stable quality of life, despite living with illness or disability (Andrykowski, 1993). Sprangers and Schwartz (1999) relate this phenomenon to response shift, shown in Figure 3, which is an alteration of internal standards, values, or conceptualisation

(redefinition) following an event such as a change in health status. According to Sprangers and Schwartz, being diagnosed with a chronic illness may trigger behavioural, cognitive, and affective processes (mechanisms), such as social comparison, reprioritising goals, and modifying expectations, thus enabling an individual to maintain a suitable quality of life despite deteriorating physical health. An individual's choice of mechanisms and the degree and choice of response shift may also be influenced by dispositional characteristics (antecedents), such as socio-demographics, personality, and expectations. In the event that an optimal quality of life is not attainable, individuals may choose a different mechanism to maintain or enhance their quality of life (Sprangers & Schwartz, 1999).



*Figure 3.* A theoretical model of response shift and quality of life (QOL). From “Integrating Response Shift Into Health-Related Quality of Life Research: A Theoretical Model,” by M. A. G. Sprangers and C. E. Schwartz, 1999, *Social Science & Medicine*, 48, p. 1509. Copyright 1999 by Elsevier Science Ltd. Reprinted with permission.

The phenomenon of response shift has appeared in a recent study on chronic illness (Schwartz, Sprangers, Carey, & Reed, 2004). Schwartz et al. (2004) explored response shift in patients with multiple sclerosis who appeared to display stable quality of life outcomes (fatigue, limitations in psychosocial and work roles, psychological well-being, and self-efficacy control) after a five year follow-up, based on pre-, post-, and then-test ratings. Findings showed specific response shift gains relating to a change in internal standards (recalibration) and re-conceptualisation (Schwartz et al., 2004). However, Sharpe and Curran (2006) argued that the context of an individual's life may also influence whether a particular strategy is suitable to facilitate adjustment to illness, such as experiencing positive adjustment through a supportive family, compared with negative adjustment from a family in conflict.

### **Finding Benefits From Chronic Illness**

Positive outcomes have also ensued following adjustment to adversity, such as chronic illness and other stressful life events. For example, the alleviation of distress (Park & Folkman, 1997) and acceptance. Positive outcomes are the adaptive beliefs a person holds regarding the benefits that arise from adversity (benefit finding) (Affleck & Tennen, 1996). Whilst a re-appraisal of threatening events, such as chronic illness, has been associated with positive adaptational outcomes (Affleck & Tennen, 1996), not all outcomes following a search for meaning are positive, which may either reflect problems with integrating situational and global meaning or negative changes in global meaning (Park & Folkman, 1997). Studies have developed insight into benefits that can ensue from chronic illness, such as interpersonal benefits (Danoff-Burg & Revenson, 2005) and life satisfaction (Kutner, Brogan, Hall, Haber, & Daniels, 2000), which imply that positive outcomes are possible despite adversity, such as chronic illness.

A longitudinal mixed-methods study by Danoff-Burg and Revenson (2005) explored the positive impact of illness on relationships for patients with rheumatoid arthritis (RA). Most of the patients (71.3%) described interpersonal benefits from illness, with 16.2% describing other benefits and 12.5% not finding any benefits. A prominent theme was appreciation of support from loved ones, such as family members and friends, but there were also reported benefits from less intimate relationships, such as interactions with medical professionals. Patients also found meaning by providing education to others (support group members, co-workers).

A prospective longitudinal study by Kutner, Brogan, Hall, Haber, and Daniels (2000) compared changes in functional impairment, depression, and life satisfaction between older patients with end stage renal disease (ESRD) on haemodialysis and non-ESRD controls. Reported life satisfaction at baseline was also lower for ESRD patients than for non-ESRD controls, but there was no significant difference between the two groups at follow-up. Kutner et al. attribute this to ESRD patients experiencing a level of adjustment to their life satisfaction by the time of the baseline interview with the difference diminishing at follow-up.

Individuals with chronic illness may also benefit from displaying optimism. For instance, a review by Scheier and Carver (1993) examining the research on the power of positive thinking, in particular the benefits associated with an optimistic orientation, found that optimists tended to accept the reality of their stressful encounters and appear intent to grow from adverse experiences, including “making the best of bad situations” (p. 28). Conversely, pessimists had a tendency to deny the existence of stressful events or avoid attending to problems or stop making an effort when difficulties emerge. According to Scheier and Carver, these differences in

coping contribute, in part, to differences in distress experienced between optimists and pessimists.

### **Social Comparison and Chronic Illness**

Social influences can also impact on individuals' experience with chronic illness (e.g. illness management, well-being, and quality of life) with the potential for positive and negative outcomes. For instance, in Chapter 2, studies by Kaba et al. (2007), Barbara and Krass (2013), and Krepia et al. (2011) showed the influence of the social environment on the perceived social consequences of chronically ill individuals, which potentially influenced their coping procedures (adherence to treatment regimen to manage illness) and outcomes (quality of life).

Social comparison is another social influence which, according to Leventhal et al. (1997), may serve different functions depending on the situation, resembling a type of coping procedure with particular needs and motives which are situation-specific (person-situation interaction). For example, the use of social comparison to improve mood and psychological well-being (Wills, 1981). Upward social comparisons have been used to evaluate one's abilities against others perceived to be better than the self, which had a negative impact (Suls, Martin, & Wheeler, 2002). Conversely, downward social comparison refers to an individual's comparison with one or more others who are less fortunate than the self in order to reduce negative affect and improve self-esteem (self-enhancement) (Wills, 1981). For instance, downward social comparisons have been associated with positive affect for patients with chronic illness (diabetes) (Gorawara-Bhat, Huang, & Chin, 2008). However, individuals' self-enhancement through downward social comparison has been challenged (Buunk, Collins, Taylor, VanYperen, & Dakof, 1990; Collins, 1996). Buunk et al. (1990) found that cancer patients' affect, following self-evaluations

through social comparison, could be either positive or negative indicating that the direction of comparison was not relevant. According to Collins (1996), the effect of social comparison is also dependent on individuals' interpretation (self-construal) of their social comparison with others.

### **Social Networks, Social Support, and Health**

Although social networks and social support are types of social influences that are intended to have a positive impact on health, negative impacts on health can also ensue. Whilst social integration refers to the presence of social ties, social network describes the network of social relationships encompassing individuals (Heany & Israel, 2008). A conceptual model proposed by Heany and Israel (2008), shown in Figure 4, illustrates the relationship of social networks and social support with health. The numbers in parentheses that follow refer to the numbered pathways shown in the model in Figure 4. The model includes a direct pathway (1) that links social relationships and social support to health. Supportive network ties that satisfy basic human needs, such as companionship, a sense of belonging, intimacy, and a reassurance of self-worth, may enhance an individual's health independent of stress level. Two other pathways include an effect of social networks and social support on coping resources (2) and community resources (4). The ability to evaluate and solve problems as well as the provision of access to new contacts and information can be strengthened through social networks and social support. Furthermore, a perception of personal control over situations may increase if the provision of support helps reduce uncertainty or unpredictability or facilitate preferred outcomes. Research on the potential influence of social networks and social support on organisational and community competence is limited. However, Heany and Israel envision that social networks and social support may enhance resource gathering and problem solving

within a community, which may have direct effects on health or indirectly by reducing or ‘buffering’ the effects on health through exposure to stressors. Another pathway (3) suggests that social networks and social support may be influential in the duration and frequency of exposure to stressors which are related to improved mental and physical health. Social networks and social support may also influence and support individuals in health behaviours (5), including illness behaviour, and sick-role behaviour, and thus impact on disease related incidence and recovery.

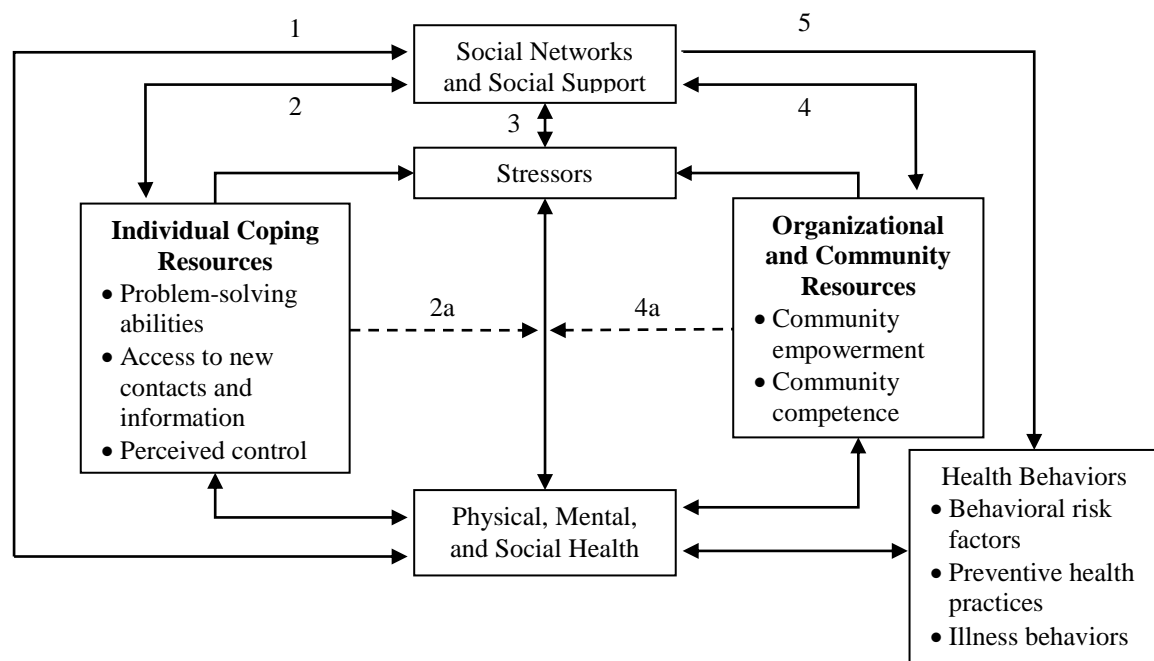


Figure 4. Conceptual model for the relationship of social networks and social support to health. From *Health Behavior and Health Education*, 4<sup>th</sup> Edition (p. 194), by K. Glanz, B. K. Rimer, and K. Viswanath, 2008, San Francisco, California: Jossey-Bass. Copyright 2008 by John Wiley & Sons. Reprinted with permission.

According to Berkman and Glass (2000), multiple types of support can influence health, and social support may vary by type, frequency, intensity, and amount of support. Social support is divided into four subtypes, namely emotional,

instrumental, appraisal, and informational support. Emotional support is the provision of empathy, love, and caring provided by another person, usually by a close friend, partner, or confidant. Instrumental support relates to assistance with tangible needs, such as household tasks and the provision of finance (money). Appraisal support refers to the provision of feedback and help with decision making, such as deciding on a course of action. Finally, information support refers to the provision of advice and information to address specific needs. Differences between cognitive and behavioural aspects of social support reflect differences between actual support and perceived support (Berkman & Glass, 2000). For instance, the intention of the social support provider is to be helpful, which differentiates social support from negative social encounters that are intended to undermine such as being critical or annoying, but the receiver of the intended helpful support may perceive or experience the support as unhelpful (Heany & Israel, 2008).

Berkman and Glass (2000) argued that focussing on social support as the only key approach through which social networks impact on mental and physical health excludes a consideration of the social context and structural underpinning associated with the provision of social support. According to Heany and Israel (2008), interconnections between individuals (social networks) may also provide other functions besides support, such as companionship, social comparison, social influence, social undermining, and social control (Heany & Israel, 2008).

Social support may also be influenced by the perceptions of dependence or independence for individuals with chronic illness. According to Gignac and Cott (1998), the subjective perceptions of individuals with chronic illness or disability may influence the nature of the assistive relationship, such as viewing themselves to be independent when receiving assistance in domains relating to community mobility



and household tasks from close family members (spouse). A study by Gignac, Cott, and Badley (2000) explored older individuals' adaptation to chronic illness and disability and how their adaptation related to their perceptions of dependence and independence. In the domains of household activities and valued activities, assistance from others was related to an impact on independence and feeling dependent but not with feeling helpless, emotionally reactive, and reduced coping efficacy reported in most of the other domains.

### **Companionship and Health**

Another social influence on health is companionship (social interaction), which has generally been related to positive mental health and wellbeing (Rook, 1990). However, companionship may also have a negative social influence on health, such as when it is not welcomed. According to Rook, (1990), companionship and social support may address different dimensions of psychological health. For instance, social support may assist psychological wellbeing by restoring an individual's equilibrium following an adverse life event, such as reducing negative affect and reinstating an individual's baseline level of functioning. On the other hand, companionship aims to enhance an individual's level of contentment, through the use of humour, recreation, and affection. Thus, "support may be especially important in preventing mental health, whereas companionship may be especially important in fostering positive mental health" (Rook, 1990, p. 222).

Rook (1990) also noted that there are a number of processes through which companionship may be associated with psychological wellbeing. Companionship may help individuals transcend mundane problems and concerns to enhance psychological wellbeing, such as providing a temporary escape from routine preoccupations. Companionship may also help divert attention from self-scrutiny, such as focussing

on oneself and one's shortcomings which can potentially increase negative affect, such as depressed mood. On the other hand, Rook noted that some individuals may not need companionship or are content with limited companionship. Some older individuals may prefer limited social interactions or fulfil their requirements for social interaction through less frequent contact with others. Some older individuals may also experience more social interaction than they would prefer, despite their expressed low need for social interaction. For instance, they may feel their privacy is invaded when they receive unwanted visits or are forced into social encounters that they cannot decline. The next section will review several studies on the influence of social support and social interaction on the experience of chronic illness. Studies on social influences, in particular social support and social interactions, have developed insight into their positive and negative impacts on the health of individuals with chronic illness. For example, studies have shown the unintended negative impacts of social support, despite positive intentions (Gallant et al., 2007), and the buffering effect of social support against stressful life events (Bell, LeRoy, & Stephenson, 1982).

### **Patients' Experience With Social Support and Social Interaction**

Gallant et al. (2007) explored positive and negative social network influences on elderly patients' self-management of their chronic illness. Regarding negative social influences, they found that supportive intentions of social network members (friends and family members) were counterproductive when their actions unintentionally hindered the recipients, a group of older adults with chronic illnesses. For instance, social network members discouraged participants from potentially benefiting from physical activity. They also offered forbidden foods, and provided unwelcomed advice and parental overprotection. These actions emanated from feelings of concern and a desire to do something helpful.

Bell, LeRoy, and Stephenson (1982) explored the relationships amongst social support, stressful life events, and symptoms of depression to determine if social support buffered against the impact of stressful life events on psychological equilibrium. Main effects of stressful life events, social support, and socioeconomic status on depressive symptoms were found. In addition, a statistically significant conditional effect between social support and life events supported the idea that social support helps to ameliorate the adverse effects of life events. The greatest impact of stressful life events was experienced by participants in groups with lower levels of social support, whilst those in groups with higher levels of social support were buffered against severe distress. According to Bell et al., increased levels of social support help to reduce the impact of life events on depressive symptoms.

In summary, the conceptual model of adjustment by Sharpe and Curran (2006) provided an understanding of the processes by which individuals attempt to form adaptive views of themselves and the world, such as seeking meaning for their chronic illness in order to help them find order and purpose, or altering their standards or values (response shift). Studies reviewed in this chapter have shown that chronically ill individuals are capable of achieving positive outcomes in relation to their psychosocial adjustment to chronic illness. However, negative outcomes can also ensue if individuals with chronic illness are unsuccessful in negotiating the adjustment processes. Understanding the processes of adjustment to chronic illness may also help to provide an understanding of how some individuals are able to experience positive adaptational outcomes despite adversity such as chronic illness, compared with other individuals experiencing negative outcomes, which may aid in the development of appropriate interventions in this area.

Social influences have also been related to the experience of chronic illness, including coping and psychosocial adjustment to chronic illness. Social comparison of chronic illness has been shown to have a positive or negative influence on mental health and wellbeing. The conceptual model of Heany and Israel (2008) demonstrated the relationships of social networks and social support on health through direct and indirect pathways. The model proposed that indirect mediating pathways through which social networks and social support may influence health include their influence on health behaviours, their strengthening of coping resources and community resources, and their influence on the duration and frequency of exposure to stressors. Social networks as well as chronically ill individuals' perceptions of dependence and independence can influence health in positive and negative ways. Rook (1990) claimed that while social support may help to prevent negative mental health, companionship may facilitate the creation of positive mental health. Studies reviewed in this chapter also highlighted the influences of social support and social interaction on individuals' experience with chronic illness, as well as the buffering effect of social support against stressful life events. Social networks, including social support and social interaction, are important because they can influence individuals' adaptational outcomes to chronic illness (mental health, quality of life).

Following a review of the literature, a reminder of the purpose of the study seems warranted, which was to understand the experience of chronic illness for a group of elderly Greek-speaking males (referred to in Chapter 1) and how this experience has influenced their health behaviours, including management of their chronic illness. In particular, to explore this group's illness representations and coping methods including the influence of their illness representations on their methods of coping. Another purpose of the study was to explore the processes and outcomes of

their psychosocial adjustment to their chronic illness, including any social and cultural influences relating to their chronic illness experience.

## **Chapter 6**

### **Methodology**

Qualitative research encompasses a wide variety of approaches and methods of inquiry. Qualitative approaches provide an opportunity for researchers to understand “how people make sense of their world and the experiences they have in their world” (Merriam, 2009, p. 13). Marks and Yardley (2004) argued that qualitative research methods are particularly suitable for understanding the experience of health and illness because they allow subjective meanings and their socio-cultural context to be the centre of inquiry. The subjective experience of illness drawn from personal individual accounts can provide a rich source of information contributing towards the understanding of this phenomenon (Lupton, 2012). A qualitative method of inquiry based on the subjective experience of illness is, therefore, well suited to the primary research aim of the present study.

The epistemological approach chosen for this study is social constructionism. Crotty (1998) defined social constructionism as “the hold our culture has on us: it shapes the way in which we see things (even the way in which we feel things!) and gives us a quite definite view of the world” (p. 58). Furthermore, our culture influences our view of the world by bringing certain things into focus and providing them with meaning whilst ignoring other things (Crotty, 1998).

Social constructionism has been used as a framework to explore the lived experience of illness, which has also been used to inform policy decisions (Conrad & Barker, 2010). Social constructionists highlight the importance of socio-cultural systems on the meaning and experience of illness. Furthermore, social constructionism stipulates that reality “is created by individuals who act in and toward their world” (Conrad & Barker, 2010, p. S71) rather than existing and awaiting

discovery. When applied to illness, people act on, and provide meaning for, their illness rather than being passive recipients.

Cultural meanings can influence the illness experience, views of illness, social reactions to illness, as well as policies generated regarding illness. As an example, stigma or disability associated with some illnesses develops because of social, rather than biological, reasons (Conrad & Barker, 2010). A social constructionist approach to illness, therefore, assumes a serious stance towards the subjective experience of illness by “examining the personal and social meanings of illness, and exploring how illness is managed in the social contexts that sufferers inhabit” (Conrad & Barker, 2010, p. S72).

### **Research Questions**

The purpose of the present study in Chapter 1 provided a rationale for the selection of male participants from the Greek community that formed the basis for an exploration of their chronic illness experience. The research questions were developed to explore their chronic illness beliefs and perceptions using the Common Sense Model (CSM) of the self-regulation of health and illness (Leventhal et al., 2003). The CSM is a particularly suitable framework for understanding how the illness perceptions, or lay beliefs, of individuals influence their response to chronic illness. Psychological, social, and cultural aspects of chronic illness are also explored in areas such as adjustment and social influences (social support, social interaction) which may not otherwise surface when considering various socio-cultural restrictions surrounding this particular cultural group.

The aim of this study was to provide an understanding of the experience of chronic illness for a group of Greek-speaking males as a way of informing health practices.

The following research questions were developed as a proposal for the specific aims of the present study. The questions relate to the group of elderly Greek-speaking males recruited from the Greek community of Melbourne, Australia.

1. How have this group perceived their illness? In particular, what themes characterise their representations of their chronic illness in relation to the cause of their illness, the consequences of their illness, and the controllability of their illness?
2. How have this group coped with their illness? Specifically, what themes characterise their coping procedures for their chronic illness?
3. How have this group's coping procedures been influenced by their illness representations?
4. How have this group adapted to their illness? In particular, what psychological, social, and cultural themes characterise their adaptation to their chronic illness?
5. How have this group been supported through their illness? Specifically, what psychological, social, and cultural themes characterised perceived support while ill?

## **Participants**

The purposive sample in this study comprised seven participants who were Greek male migrants living in Australia, aged 60 years and over, with at least one chronic physical illness, that is, an illness that has been present for at least three months (MedicineNet.com, 2007). The demographics of the participants are shown in Table 1. The average age of participants was 76.57 years. Data regarding the participants' English language proficiency and their year of migration to Australia



was limited. Subjectively, the researcher's observation of one participant's frequent communication in segments of English during interviewing, along with his reporting that he had read Encyclopedias, suggested that this participant appeared to be quite proficient with the English language. The researcher also observed that the study's remaining participants consistently communicated in Greek throughout the interviews. However, the true extent of their English language proficiency remained unclear. According to English Proficiency (2006, cited in Greek Care, 2013b), the English language proficiency of the Victorian population of Greek Australians who were not able to speak English very well or spoke no English at all was 40% for those aged 60 to 69 years and 55% for those aged 70 years and over. Furthermore, in regards to migration statistics, the majority of Greek migration to Australia occurred during the 1950's and 1960's (Greek Care, 2013f).

Table 1

*Participant Demographics*

Pseudonym	Age (yrs.)	Chronic Illness(es)
Spiro	69	Diabetes, Kidney Disease <sup>a</sup> , Arthritis, Asthma
Harry	90	Glaucoma, Gout, Prostate, Heart, Stomach condition
Gerry	80	Spinal Stenosis
Michael	73	Chronic Obstructive Pulmonary Disease (COPD), Parkinson's (slight tremor), Schizophrenia
Bill	79	End Stage Kidney Disease <sup>b</sup>
Anthony	74	Diabetes, Kidney Disease, Triple Myocardial Infarction (heart attack) <sup>c</sup> , Prostate, Asthma
Peter	71	Coronary Artery Disease (required bypass surgery), Stomach ulcer (cured)

<sup>a</sup>Participant had a previous kidney transplant. <sup>b</sup>Participant is on home haemodialysis. <sup>c</sup>Participant has an implanted pacemaker.

This study focussed specifically on chronic physical illnesses. However, Michael had a chronic mental illness (Schizophrenia) along with his chronic physical illness (Chronic Obstructive Pulmonary Disease [COPD]). He was included in this study because his Schizophrenia, which had been regularly managed by his psychiatrist on an ongoing basis, had been in remission for two years. The author was also mainly interested in this participant's experience with COPD.

### **Instruments**

The researcher gathered demographic data, information about participants' general health and quality of life using the RAND 36-Item Health Survey 1.0 Questionnaire (RAND SF-36) (RANDHealth, 2007), and participants' illness experiences using the Semi-Structured Interview Schedule.

**Demographic data form (DDF) - Greek version.** Participant demographics, as shown in Table 1, were obtained from the DDF developed by the researcher (Refer Appendix D).

**RAND 36-Item Health Survey 1.0 Questionnaire (RAND SF-36) - Greek version.** The RAND 36-Item Health Survey 1.0 Questionnaire (RAND SF-36) (RANDHealth, 2007) was developed by the RAND corporation as part of their Medical Outcomes Study. Data collection using this questionnaire served to obtain participants' subjective reports of their general health and quality of life. The results of the questionnaire were intended to provide a reliable and valid measurement of each participant's state of health and disability. It consisted of 36 items spanning eight dimensions, which included physical functioning, bodily pain, role limitations due to physical health problems, role limitations due to personal or emotional problems,

emotional wellbeing, social functioning, energy/fatigue, and general health perceptions. A single item relating to perceived changes in health was included as a separate measure to the eight dimensions. Item responses included Likert-type and yes/no format.

**The semi-structured interview schedule.** Semi-structured interviews can create rich data. They also allow rapport and empathy to be facilitated between interviewer and interviewee, an exploration of interesting areas, and an investigation of the interviewee's areas of interest or concern (Smith, 1995). Semi-structured interviews are an appropriate form of data collection in health-related research as they are guided by open-ended questions to elicit the subjective experience of illness. Dew (2007) suggested that semi-structured interviews provide participants with the flexibility to discuss themes or issues in their own way. Participants may also introduce themes or issues of interest not considered by the researcher, thus providing idiographic aspects of the participants in the study in contrast to the nomothetic nature of quantitative studies. Semi-structured interviews are also a form of narrative. Hydén (1997) indicated that narrative provides the advantage of exploring the experience of illness from various perspectives, including “as a social and cultural construct, as a transformation and expression of bodily suffering, and most of all as the suffering person's attempt to construct his or her world, to find his or her own life-work and life context” (p. 64).

Interview questions were developed based on the literature on common-sense, or lay, beliefs about illness and are shown in Appendix F. The topics explored in the semi-structured interviews included:

1. Beliefs about illness representations: identity, cause, consequences, timeline, cure/control

2. Coping styles and strategies
3. Psychosocial adaptation
  - reactions to illness
  - adjustments to illness
4. Socio-cultural factors of illness
  - Masculinity/identity
  - Childhood experiences
  - Cultural health beliefs and practices
  - Migration/acculturation
  - Social support/interaction
5. Experience with health service providers

The 'Information to Participants' form, consent form, demographic data form, RAND SF-36 questionnaire, and semi-structured interview schedule were created and translated from English to Greek (refer Appendices B, C, D, E, and F). Translation tools used were the Microsoft Office Word 2003 translation tool and Greek/English translation dictionaries, primarily from Pring (2000) with Stavropoulos and Hornby (1977) used as a secondary source. The researcher also used his Greek background knowledge and experience to make some minor changes to the nuances, subtleties, and meanings of the translated documents to simplify the research participants' understanding of the content. As the participants' first language is Greek, translation of the documents allowed the procedures of the interview to be understood by participants in their native language.

The researcher translated the RAND SF-36 from English to Greek and a NAATI-accredited professional translator performed the back-translation. Three of the items were altered following the translation procedures to simplify the level of understanding for the participants. The original English version and the back-translated version are presented in Appendix E, along with details of the changed items in table E1 in Appendix E.

The researcher also translated the questions for the semi-structured interview schedule from English to Greek. Pilot testing of the schedule prior to conducting interviews with participants also helped enhance the credibility of the findings, particularly for cross-language studies (Squires, 2008).

With the exception of the RAND SF-36 questionnaire, translated documents were reviewed by two members of the Greek community who were of a similar demographic to the participants in the study. They provided feedback which helped simplify the translated content to suit the participants' level of understanding. The semi-structured interview questions were presented to two additional members of the Greek community for further comments and feedback.

## **Procedure**

Four participants were recruited from Greek community clubs. The researcher attempted to contact forty-three clubs from the Greek Organisations Directory (Greek Care, 2013c). However, contact could only be established with 17 of the 43 clubs and arrangements were made with these 17 clubs to approach participants for recruitment. In the first instance, the president of each of the 17 clubs was contacted by phone and verbal consent sought to approach and address club members at the club premises. According to Namageyo-Funa et. al. (2014), collaboration with gatekeepers trusted by participants can help facilitate recruitment. The gatekeepers in the present study included the presidents of the Greek community clubs and the manager and head nurse of the Greek aged care home. During a visit to each of the club premises, written consent in both Greek and English was sought from each club president, who was also provided with a written research summary in Greek. The use of additional recruitment tools may also help to facilitate participant recruitment (Namageyo-Funa et. al., 2014). In the present study, the researcher's initial attempts

to recruit participants involved addressing all club members together with a verbal summary of the research in Greek and sought invitations from interested males with a chronic illness to participate in the study. This approach also appeared to be the most appropriate given that this population of Greek males were retired and it appeared that their contact details were not accessible other than by addressing them directly through the Greek clubs where they congregated on a weekly basis. A second recruitment tool used by the researcher was to engage in informal conversations with participants close up at their tables whilst at the club premises. Thus, when club time permitted, the researcher attended each table to further discuss the research with the Greek males and answer any questions. Club members were told the research would be conducted at a mutually convenient date and time in the privacy of their own homes. The researcher also recorded address and contact details of interested club members who were followed up by phone to arrange a mutually suitable date and time to take part in the study. Cards with contact details were also given to each club president to distribute to any participants who might have been interested in participating but were perhaps apprehensive about expressing their interest in the presence of other club members.

Two participants were recruited from a high care unit in a Greek aged care home because the researcher felt that they would also provide an interesting comparison of illness experience with the other participants living in the community. Six aged care homes were initially contacted. The manager of one aged care home indicated that there were residing candidates with chronic illness. A meeting was arranged with the aged care home manager to explain the purpose of the research and to obtain written consent. With the help of the head nurse, who reviewed the residents' records to identify residents with a chronic illness, five residents were

approached and invited to take part in the study. One resident initially agreed to be interviewed. However, he withdrew his consent following his ongoing concern about confidentiality. Two other residents reported that they had no chronic physical illness and did not participate in the study. Written consent was sought from the remaining two consenting participants who were each interviewed in their rooms.

One participant was recruited through contacts in the Greek community. He was contacted by phone and a suitable time was arranged for interviewing.

The English language skills of the participants in this study were not as advanced as those of their Greek native language. Furthermore, many of the Greek-speaking males in this study were unaccustomed with self-report instruments, which may have potentially made it difficult for them to understand and perform self-report measures. It was therefore evidently appropriate for the researcher to conduct the data collection process in the participants' first language given that the participants were more comfortable conversing in the Greek language, which also contributed to rapport building and increased participant engagement.

An ethics application was submitted and ethics approval was sought and provided by the Victoria University Human Research Ethics Committee in 2007 (Refer Appendix A).

Pilot testing was performed on a 77 year old male with arthritis who was interviewed in his home and asked for feedback at the completion of the interview. The results of the pilot testing highlighted the importance of field notes post interview to record any relevant information that might have emerged during the interview process outside of the audio-taped semi-structured interview. Pilot testing also revealed the need to elaborate with further questioning when interviewing participants.

At the commencement of participant interviews, the researcher initially engaged in social conversation with each participant as a way of building rapport. Furthermore, rapport appeared to be maintained despite the administration of the demographic data form and the RAND SF-36 questionnaire prior to the semi-structured interview schedule. With the exception of the aged care participants, the researcher was also offered and accepted Greek coffee and/or snacks. The researcher decided to exclude female partners from taking part in the interviews because one participant's spouse was invited to take part in the interview but declined. Also, three of the participants' female partners had other commitments precluding them from participating, whilst another participant had no female partner, and the two remaining participants' partners were deceased.

Although the researcher asked participants if they had a quiet room in which to conduct interviews in each of the participants' houses, this was not always available. In these cases, the researcher then asked participants if they were comfortable with conducting interviews in an environment where there may be intrusions or interruptions. Participants indicated that they were satisfied with and did not feel uneasy about being interviewed in any part of their home environment which they viewed as safe and comfortable. As an example of intrusions and interruptions, the spouses of two participants occasionally came within close proximity of the interviewing area for brief intervals. Furthermore, in one of these cases, a family friend and his wife were visiting at the time and were sitting in an adjacent open area. However, the participant also arranged for the male to participate alongside him in the interview given that the male had agreed, during recruitment at the club, to also be interviewed for the research. The researcher kindly reiterated to the male and the participant that a dual interview was not possible and was politely asked to leave the



interview area. In regard to the aged care participants, the researcher organised with staff to conduct interviews in each of the rooms of the two participants.

The researcher read the 'Information to Participants' form and consent form, as shown in Appendices B and C, and then sought consent, which was followed by the researcher reading and recording participants' written responses to the Demographic Data Form and then the RAND 36-Item Health Survey 1.0 Questionnaire (short-form). Interviewing is preferred over self-administration when dealing with people suspected of having insufficient reading skills (McHorney, 1996).

The semi-structured interviews were audiotape recorded and based on open-ended questions, as outlined in Appendix F. The duration of the audio-taped semi-structured interviews ranged from 35 minutes up to 2 hours and 55 minutes. The researcher sought elaboration from participants with further questioning as required in order to gain a broader understanding of their lived experience with chronic illness. The participants were debriefed about the purpose of the interview at the completion of each interview.

### **Data Management and Analysis**

**Translation and transcription processes.** Twinn (1997) argued that it is more appropriate for researchers to use the language of participants in health-related research when English is not their first language in order to facilitate an understanding of their health experiences, as well as perceptions regarding their health care. This task is simplified when the researcher is also the translator. According to Shklarov (2007), when the researcher is also the translator:

Seeing two parallel cultural meanings or realities, and hearing two or more conceptual understandings might be challenging, but if not obscured, it might meaningfully enrich the in-depth perception of the context area and

contribute tremendously to the ethical sensitivity and the quality of the research. (p. 532)

Reliability is also enhanced during the translation process when only one translator is used (Twinn, 1997). Furthermore, achieving conceptual equivalence, or a comparable meaning between the source and target languages, is aided by the researcher's proficient understanding of the language as well as an intimate knowledge of the culture (Chen & Boore, 2009).

Along with completing tertiary education courses in English, the researcher in the present study completed the first two years of secondary education in Traditional Greek and the remaining four years of secondary education in Modern Greek. The researcher also used the Greek language with his family of origin. His father was also of a similar demographic to the participants in the study. The researcher was, therefore, well suited to the additional role of translator in this study.

The researcher used his knowledge and experience of the Greek language and also referred to the Greek/English translation dictionaries of Pring (2000) and Stavropoulos and Hornby (1977) to translate the audio recordings of participants' interviews from Greek to English during transcription. Throughout the translation and transcription process, aspects of the recordings were repeatedly listened to carefully in order to clarify the meaning of participants' stories whilst taking into consideration surrounding contextual information (Marshall & Rossman, 2006). Transcripts ranged in size from 15 pages up to 47 pages. Participants' excerpts in their original form, taken from the researcher's translated transcripts for each of the semi-structured interviews, have also been included (refer Appendix G) for comparisons with participants' excerpts in the findings. Back translation is typically undertaken in quantitative research to ensure linguistic and conceptual equivalence of established

measures. In this study, the researcher was interested in having transcripts back-translated. However, the fact that the researcher is bilingual reduced the need for that process because, as a cultural insider, the researcher has knowledge that allowed him to understand the messages conveyed. The researcher also realises that this is not perfect and that there are limits, but back translation is not fool proof, and in this case, the present study's research is constructionist and involves interpretation.

Furthermore, during interviewing, the researcher often checked his understanding of participants' narratives through interviewing techniques that included active listening, clarification, and paraphrasing in an attempt to ensure that participants' information had been interpreted correctly. Having said this, the researcher also had real pragmatic constraints (budgetary) that made the step of back-translations of participant semi-structured interview transcripts from English to Greek by a National Accreditation Authority for Translators and Interpreters Ltd. (NAATI) accredited translator impossible.

**Thematic analysis.** Illness experiences have been analysed by various methods, including Interpretive Phenomenological Analysis (IPA) (Clarke, McCorry, & Dempster, 2011; Edwards, Thompson, & Blair, 2007; Hale, Grogan, & Willott, 2009) and Thematic Analysis (TA) (Campbell & Guy, 2007; Dennison, Yardley, Devereux, & Moss-Morris, 2010; Furze, Lewin, Roebuck, & Thompson, 2001). TA was chosen for this study because it is a method which allows patterns, or themes, to be identified, analysed, and reported from within the data and is also capable of providing "a rich and detailed, yet complex, account of data" (Braun & Clarke, 2006, p. 78).

The thematic analysis in the present study comprised of both deductive thematic analysis and inductive thematic analysis. Deductive thematic analysis is

based on themes related to either existing theory or prior research and relates to specific research questions, whereas inductive thematic analysis is based on themes emerging from the data (Boyatzis, 1998). A combined deductive and inductive thematic analytic approach (Charania & Tsuji, 2011; Fereday & Muir-Cochrane, 2006) was chosen for this study as it allows elements of a theory to be investigated, as well as permitting other possibilities emerging from the data to be explored. When basing themes on preconceived categories generated from theory, data can be tested in order to determine if it fits with the theory or previous research on the subject of interest. However, qualitative research is also about discovering new findings that do not match with previous theory and contribute new knowledge, which would warrant a dual deductive and inductive thematic analytic approach (Joffe, 2012). The present study used deductive thematic analysis for the first three research questions and inductive thematic analysis for the remaining two research questions. Themes were drawn from semi-structured interview transcripts.

The deductive thematic analysis in this study examined participants' illness perceptions based on the Common Sense Model of the self regulation of health and illness (Leventhal et al., 2003). Themes included participants' beliefs about the causes and consequences of their illness, and their ability to control their illness. Themes also included their ways of coping with their illness. Sensitising concepts helped guide theme and sub-theme development (Blumer, 1969), which are loosely held concepts based on theory and previous research that are described and given meaning by participants. They are also used for referencing and providing direction (Schwandt, 2007). Dimensions of illness representations (IR's) (Leventhal et al., 2003) were used as sensitising concepts. For example, the sensitising concept of 'ability to control illness through medical treatment' for the 'cure/controllability: treatment control' IR

theme, and the sensitising concept of ‘personal ability to control illness’ for the ‘cure/controllability: personal control’ IR theme.

The present study also used inductive thematic analysis to determine any psychological, social, and cultural aspects relating to participants’ adjustment to their chronic illness, based on the model of adjustment (Sharpe & Curran, 2006), as well as social influences (social support, social interaction) on participants’ chronic illness experiences. Themes included finding meaning, finding a purpose, finding benefits, and adapting to illness. Themes also included the roles of medical and social support, and the importance of social interaction. Whilst inductive themes are explored from the data, the researcher also plays an active role in the theme generation process. Acknowledgment of the researcher’s preconceived theories and assumptions are important as these can influence the choice of themes and patterns selected from the data (Braun & Clarke, 2006).

According to Braun and Clarke (2006), thematic analysis is typically associated with an identification of themes at either a manifest or a latent level. Manifest content refers to explicitly intended meaning within the data set, such as descriptions of experience, whereas latent content concerns inferred or interpreted meaning beyond that consciously intended by participants. For example, a theme of ‘courage’ in the present study was manifestly described as unaffected by illness. Yet, this appeared to mask and counteract any latent emotional consequences to feelings of vulnerability in the presence of others. In the present study, latent themes were created from the semi-structured interview transcripts. Latent themes were explored in order to gain a richer understanding of the unintended meaning of the illness experiences of participants (Joffe & Yardley, 2004).

***Deductive themes.*** Themes were developed, in accordance with the thematic analysis procedure of Braun and Clarke (2006), based on a detailed analysis of the various dimensions of illness representations (Leventhal et al., 2004). The themes addressed specific research questions related to participants' perceptions of their illness, which included participants' beliefs and perceptions about the cause, consequences, and controllability of their illness. The deductive themes that developed were then compared with previously published literature.

***Inductive themes.*** The analysis of the translated interview transcripts followed the recommendations of Braun and Clarke (2006) and consisted of six phases. The first phase of analysis was concerned with the familiarisation of the content of the transcripts. The researcher immersed himself in the transcribed texts when reviewing transcripts during the translation process, and also when generating the outlines for each of the transcripts. The second phase of analysis involved the development of the initial codes (Braun & Clarke, 2006). Code development followed the procedure of Boyatzis (1998), which involved a number of stages. The first stage involved the development of an outline for each transcript in order to summarise and reduce the raw information in the transcripts. Boyatzis calls this stage a reduction of the raw information to manageable levels prior to code development, whilst also providing familiarity and processing of transcript information. The summaries also enabled preliminary scanning for possible patterns across the transcripts. Outlines were compared and contrasted with each other to identify similar patterns in the second stage, which formed the basis for the initial codes (Boyatzis, 1998) using the participants' own words as much as possible. An example of the initial codes was 'Life is over if you become disappointment.' Contrasting patterns were also included where appropriate because "it is important to retain accounts that depart from the

dominant story in the analysis” (Braun & Clarke, 2006, p. 89). For example, a contrasting code was ‘Sometimes unable to contain crying when thinking that illness found him.’ These patterns were then checked against the original transcripts for verification, and were used to develop initial codes. The initial codes formed the basis for the development of themes, which were broader than the initial codes and included interpretation of the data (Boyatzis, 1998). An example of an inductively derived theme that emerged was ‘Finding Meaning.’ In the third phase, a thematic map was then developed, based on the list of codes generated in phase two, to create overarching themes and the relationships between the themes, codes and various theme levels. This followed a review of the themes for further refinement (phase 4), and definition and labelling of themes (phase 5) (Braun & Clarke, 2006). The themes were then related back to the research questions and the literature and included specific examples from the transcripts.

### **Rigour and Trustworthiness**

**Triangulation.** Triangulation, which can include data sources, multiple researchers, multiple theories, and various methods, is said to strengthen the validity of claims to knowledge (Marshall & Rossman, 2011). Semi-structured interviews were used as the primary data collection methods in the present study, which were supported with the researcher’s field notes and information from demographic data and the RAND SF-36 questionnaires.

**Audit trail.** “In research, the audit trail is used to evaluate decisions and analytic procedures throughout a study to demonstrate the soundness, appropriateness, and in essence the validity of conclusions” (Salkind, 2006, p. 60). Studies of qualitative research often involve modifications because not all of the study’s parameters can be anticipated in advance. As a result, documentation needs to be

recorded for any decisions, including the rationale for such decisions as a way of verifying the appropriateness of the decisions made.

The use of field notes provides a rich source of contextual information that cannot be captured by audio recordings and can help contribute towards a richer understanding during reporting of the research (Rodgers & Cowles, 1993). In this study, the researcher recorded field notes immediately following each interview.

The methodological decisions made in the present study were recorded, including the rationale for each decision, to maintain investigative rigour of the methodology (Rodgers & Cowles, 1993). For instance, in regard to documentation of changes associated with data collection, any changes to the initial semi-structured interview questions made following consultation with Greek members of a similar demographic to the research participants, as well as interview question changes emerging subsequent to pilot testing. As a further example, changes that occurred during both the deductive and inductive thematic analytic procedures, such as collation and grouping of codes prior to theme development, were also recorded.

The researcher's processes throughout the analytic processing of the data, including thought processes relating to the various steps of the analysis, such as code development, and the development and refinement of themes and sub-themes were recorded in memos (Birks, Chapman, & Francis, 2008; Saldaña, 2009). This provided a way of backtracking through the analytic steps to ensure rigour and determine that reasonable measures were taken into account throughout the process of analysing the data (Rodgers & Cowles, 1993).

## **Ethical Considerations**

**Personal reflection.** Unlike quantitative data collection, such as the use of questionnaires, the influence of the researcher during the semi-structured interview



process cannot be removed (Dew, 2007). Reflexive recording of the researcher's role in the data collection and analysis, including his personal characteristics, attitudes, biases, and assumptions, was included to determine their possible influence on the shaping of the methodological processes (Dew, 2007; Mays & Pope, 2000). The importance of researcher reflexivity in qualitative research must not be underestimated, particularly as it allows the effects of the researcher's assumptions, intentions, and actions on the research investigation to be made explicit (Yardley, 2000). Furthermore, the interplay between researcher and data is crucial to the generation of knowledge that reflects the breadth and depth of human experience" (Birks et al., 2008, p. 69). Using critically reflective research journals provides the opportunity for changes to be made to the research design as needed (Ortlipp, 2008).

In the present study, the author, who was also the interviewer, reflected upon the influence that his own cultural background as a Greek Australian might have had on the research methodology, including his approach to interviewing and data analysis.

First, the interviewer was considerably younger than the research participants, with up to approximately 40 years difference in some cases. This made him feel that they were like fathers who were in positions of authority, who needed to be respected and listened to as men of his father's generation.

Second, the interviewer felt, in part, that being born Greek as well as communicating in the Greek language with his parents during his early childhood and attending Greek education, up to year 12, would enable him to establish rapport relatively easily with participants during interviewing. However, when the interviews commenced, he felt at times that participants appeared to have a more proficient use and understanding of the Greek language than he had. This appeared to influence the

progress of the interview with some participants. For example, whilst interviewing one particular participant, the interviewer experienced some difficulty in understanding the participant's language, particularly when the participant attempted to articulate the word 'impotency', which sounded like 'ipothesi' to the interviewer. This appeared to agitate the participant, leading to deterioration and eventual early termination of the interview process, despite the interviewer attempting to reassure the participant and re-establish rapport after feeling guilty for contributing to the participant's agitated state following the misunderstanding.

The interviewer also felt that his own assumptions about elderly Greek male migrants from his own life experience, such as their general reluctance to reveal their vulnerabilities or discuss their feelings, might prejudice the interview process as well as the data analysis and interpretation. The interviewer thus attempted to counteract this influence by bracketing his assumptions as much as possible during these stages of the research.

## **Chapter 7**

### **Common Sense Model (CSM) Illness Representation Themes**

The findings of the present study have been organised into two chapters. All of the themes presented in the findings chapters have been derived from thematic analysis of interviews with participants. The present chapter presents themes of illness representations relating to the Common Sense Model (CSM). Chapter 8 presents themes concerning coping procedures that are shaped by illness representations of the CSM. Chapter 8 also presents psychosocial themes and cultural aspects that reflect processes and outcomes associated with individuals' psychosocial adjustment to their chronic illness, as well as social influences on chronic illness. Thematic analysis of illness representations for participants in this study will provide insight into their CSM beliefs regarding their chronic illnesses.

### **Common Sense Model (CSM) Illness Representation Themes**

The present chapter presents themes based on illness representations from interview material, expressed in terms of the CSM (Leventhal et al., 2003). Illness representations are participants' beliefs regarding their chronic illness, which are based on knowledge and experience (Leventhal et al., 2001). They can be used to develop goals for illness self-management and guide coping procedures for attaining goals or managing health threats, as well as standards for evaluating response self-efficacy. Individuals' appraisal of the effectiveness of their coping procedures can also reciprocally influence their illness representations (Leventhal et al., 2003). The illness representation themes are presented in Table 2. The identity attribute has been integrated within the themes and the timeline attribute was omitted because all participants' perceived their illness to be chronic in nature. Excerpts from interview transcripts are presented to illustrate each of the themes.

Table 2

*Illness Representation Themes Relating to the Common-Sense Model (CSM)*

Themes	Subthemes
Cause	‘My body’
	Heredity
Physical consequences	Importance of routine
	Impact on physical activity
Psychological consequences	Cravings
	Importance of self-control
	Emotional responses
Social consequences	Concerns about others’ reactions
	Social comparison
	Non-disclosure
Cure/Controllability: Treatment control	Reliance on medical professionals
	Reliance on medical equipment
Cure/Controllability: Personal control	Lifestyle behaviour
	Self-control

**Illness cause.** This illness representation relates to participants’ views regarding the cause of their illness, such as a family history of illness or illness caused by environmental factors (Scharloo & Kaptein, 1997). The themes regarding the perceived cause of illness comprised a number of sub-themes, which included ‘my body’ and heredity.

One participant, Michael, perceived environmental stressors (stressful life events such as loss of business and house), including an emotional response (worry)

and prolonged, heavy smoking to have contributed to the cause of his illness (chronic obstructive pulmonary disease [COPD]):

*I made a business and I lost it and the bank took my house and sold it. Those bring on whatever illnesses I had, and the cigarettes. I smoked so much, about thirty years. (Michael)*

*The illness naturally came from the worry, and from those that I went through. (Michael)*

**‘My body’.** One participant (Harry) attributed his illness to bodily anomalies, which suggested a physical cause consistent with the concept of mind-body dualism and the biomedical model, where the body is viewed as a machine and a separate entity from the mind (Samson, 1999a). Harry’s belief that his body was not just the site but also the cause of his illnesses (glaucoma, gout, prostate cancer, chronic stomach condition [intestinal inflammation]) also suggests that he viewed a clear distinction between mind and body, with the latter causing his illness. This may have also influenced his reliance on medical professionals as well as his adherence to medication:

*The body brings them up. Our body produces them. I don’t produce them. (Harry)*

Harry also perceived the effects of bodily ageing to be an influential factor regarding the cause of his illness, which he explained using an analogy:

*Like damage to the spark plugs when they don't get oiled, that's how a person's engine is, when his rheumatism bothers him. Because the age passes, like the car, as its age passes, everything damages. (Harry)*

Illness symptoms have been attributed to ageing by the elderly, particularly for mild symptoms (age-illness rule) (Martin et al., 2003). However, Harry's belief that the body deteriorated with age suggests that either age may have increased the possibility of illness and symptoms of illness or symptoms may have resulted from the combination of age and illness (Prohaska et al., 1987).

***Heredity.*** Heredity was also associated with the cause of illness for some of the participants. Anthony believed that the development of his illness was associated with an unmodifiable risk factor relating to a family history of diabetes:

*They reckon someone in the family 100 years back had it, and they say that it originated from the father, not from the mother. My mother did not have sugar, but someone in her family could have had sugar, and it comes to me. (Anthony)*

Although hereditary factors may have increased his susceptibility to diabetes, other modifiable environmental risk factors, such as obesity, dietary habits, and inadequate physical activity, also interact with hereditary factors to contribute to the onset of diabetes (Australian Institute of Health and Welfare, 2013). It was unclear whether Anthony was aware of these environmental risk factors as possible causes of

his illness. Peter believed that a familial inheritance associated with a susceptibility to stress had contributed to his illness (coronary artery disease):

*The stress is inherited, a big worry. It's stress. It's inherited. (Peter)*

Inherited personality traits, in particular negative personality traits, such as being stress prone, can be a risk factor for disease (Smith & Ruiz, 2002).

In summary, causes of illness were externally attributed to stressful life events, heredity, and bodily organ deterioration moderated by age. Externally attributed causes of illness could potentially influence coping procedures and illness outcomes, depending on the degree of responsibility assumed for the cause of their illness. Causal beliefs of illness were also generally consistent with the biomedical view of illness (Yuill et al., 2010).

**Consequences of illness.** This dimension represents participants' ideas regarding the potential consequences of their illness. According to Scharloo and Kaptein (1997), consequences include participants' perceptions regarding the short-term and long-term effects of their illness, which are typically categorised according to physical, psychological, and social consequences. These three categories also form the basis for the sub-themes in this section.

*The physical consequences of illness: Importance of routine.* Several participants emphasised the importance of daily routine as a consequence of their illness, which ranged in severity from self-monitoring to the use of life sustaining equipment. There were serious consequences for Michael and Bill who relied on the daily use of life sustaining equipment in order to live:

*The breathing was hard. They gave me the oxygen for that reason. The oxygen is always three, four times a day. Without the oxygen, I cannot live.*  
(Michael)

*I know the situation with the kidneys will not pass now! I can't not do those [things] that they tell me, I have to do them, because if I don't do them, I'm finished, because when the kidneys work 5, 6 percent, it's very serious.* (Bill)

Anthony also perceived that there were consequences in his attempts to control his blood sugar levels, such as his previous experiences with hypoglycaemia (low blood sugar level), which may have influenced his dietary habits:

*This morning it [blood test] was five, yesterday it was 11, the day before 13. It doesn't matter what you eat. It doesn't matter if I don't eat.* (Anthony)

*If I'm not careful and I don't eat three times in the morning at different periods, the sugar will fall to 0.2, in which case I might collapse into a coma. I have had it happen twice. Twice I went to the hospital.* (Anthony)

***The physical consequences of illness: Impact on physical activity.*** One participant perceived that his illness resulted in limited physical exertion. Peter believed that his illness had limited his ability to physically exert himself:



*When we walk [or] run, we will feel pain, we will swell up, we will stop... we can't bend down to work, to lift weights. Many alternatives are not possible with a heart operation. (Peter)*

In addition to physical restraint, Peter displayed caution in other areas (behaviour, lifestyle) because of his concern for his heart:

*Not even to develop stress, to be seated on the chair, and to start smoking because that is also work. Not one thing or the other. The cardiac [system] should not overwork. (Peter)*

Peter's surgery was performed 15 years prior to interviewing. However, limits on physical exertion following coronary artery bypass graft surgery (CABG) typically applied to the first few months following surgery activity (Briffa et al., 2006; National Institutes of Health, 2013). Peter's cautious approach to activity involving lifting and bending, following the recovery period, may have resulted from a lack of awareness that this restriction mainly applied to the recovery period. His cautious approach may have also been reinforced by his perception, and perhaps fear, regarding the death of others in similar situations:

*Many involving those went out of necessity for work, and they ceased in their work. (Peter)*

Bodily weakness was also perceived by a few participants to be another consequence of their illness:

*I don't have the facility of the body to react. (Bill)*

*You feel that you are a cardiac, worn out by the heart. (Peter)*

Furthermore, perceptions of reduced strength with illness appeared to be influenced by age and other co-morbid conditions:

*When a person is well, he's strong, but when he starts to get ill. I'm reaching 80, consequently everything comes, and when they come, they don't leave easily, whatever it is, and more so the kidneys. (Bill)*

*With age, man experiences a lot because the body wears out. There isn't a person who lives beyond 70. I don't know someone who doesn't have pressure, who doesn't have cholesterol, who doesn't have bad illnesses. (Harry)*

In summary, physical consequences included serious consequences associated with a reliance on life sustaining equipment. Other physical consequences, such as limitations to physical exertion and reduced strength, imposed restrictions on quality of life. Along with illness, age and other co-morbid conditions appeared to influence perceptions of reduced strength. At other times, age was attributed to be the cause of illness (age-illness rule) (Martin et al., 2003).

***The psychological consequences of illness: Cravings.*** Some of the participants reported consequences associated with cravings. After being diagnosed

with chronic obstructive pulmonary disease (COPD), and complying with his doctor's advice to stop smoking, Michael experienced a strong craving to smoke, driven by a 55 year history of smoking:

*I had to stop smoking and it is three weeks since I last smoked. I crave it but I cannot smoke. (Michael)*

Anthony, a diabetic, craved sugary food, such as sweets. Although oral cravings for certain foods are not symptoms of diabetes, they could have contributed to the onset of diabetes, through a history of eating patterns prior to the development of diabetes, which may have fulfilled an emotional need (Everyday Health Media, 2013):

*I have a weakness. I like to eat something. I like to grab something which is sweet. I want it and I can't, or I grab it and I become ill, one of the two. (Anthony)*

Despite claiming a need to be "patient" and to display "caution", Anthony went on to express his resignation about his inability to moderate his daily food intake:

*With a little patience, and with some caution, in whatever I grab, in whatever I eat. I always make the mistake and eat more [than I should]. I like to eat. I go through that each day, the same routine. I can't do anything else. (Anthony)*

***The psychological consequences of illness: The importance of self-control.***

Several participants perceived that there were consequences to not adhering to the requirements associated with the control of their illness. Bill perceived that he needed to monitor, accurately estimate, and carefully control all of his daily fluid consumption, including certain foods, out of necessity, in order to avoid serious consequences for his kidneys:

*Salt is prohibited. Very little water, I'm allowed one litre a day. No Feta cheese at all, because of the salt. (Bill)*

However, his daily routine also appeared to affect his quality of life in relation to dietary restrictions:

*I'm thirsty and I crave a glass of water, to enjoy it, to drink lemonade, to drink something and I can't. If I drink, for example, half a glass of lemonade, I have to estimate how much of the day's total it is, so that I am about on one litre. As a person, I also like to eat a nice meal, to drink a glass of beer, to drink a glass of water, I can't. [It's] difficult. (Bill)*

Anthony perceived that he needed to be constantly aware of the requirements for daily symptom management because he believed that environmental cues had a tendency to trigger negative thoughts about his illness (diabetes), leading to negative affect and an exacerbation of his illness:

*It needs a lot of attention, to know what you have, to know how you will get through it, even for a few minutes, in case you forget it, and from there onwards, you're okay. Or you shouldn't think about it at all. Something that can't happen, it can't. Somewhere in the day you'll think, either from the walking, or your food, or from the medication you take, or something else that might happen, you immediately think that you don't feel well, and even if you are feeling well, you don't feel well. One affects the other. (Anthony)*

Furthermore, his thoughts were frequently focussed on the treatment requirements for his illness, prompted by daily visual reminders relating to the management of his illness:

*It's not like drinking a glass of water, and drinking a glass of wine, and you say, "I won't think about the wine today, I'll think about it the day after tomorrow." I think about that every day. I can't say that when I get up in the morning, I won't find my medication there, I can't see that the insulin does not exist, I can't see that there isn't the injection and I have to inject, therefore you think about it every day. (Anthony)*

Anthony also struggled with resistance to his daily self-monitoring, indicating how difficult it was to adapt to the requirements for managing his illness:

*I can't even tell my wife I don't want to do the tests today, because I don't like to do the tests. I have to do it to see where it is! (Anthony)*

***The psychological consequences of illness: Emotional responses.*** The development of an emotional response (anxiety) was another consequence of illness for some of the participants. Emotional responses to illness are an important component of the CSM and can potentially affect coping procedures, for example, undertaking avoidant coping or emotion focussed coping strategies, as well as illness outcomes. Emotional responses have thus been included with themes relating to the psychological consequences of illness. Bill believed that anxiety was an expected consequence of illness, congruent with his emotional reactions to various facets of his illness:

*When a person is healthy, he's healthy, but when a body starts to become ill, what else is there but worry. (Bill)*

Bill also experienced anxiety and another emotional reaction (sadness) in relation to uncertainty about his future with illness, as evident in the following excerpts:

*As much as it is, it creates worry in you, sadness in you. Like a person who has proper kidneys that work properly compared with me who has damaged kidneys, that affects me a lot. The everyday, and the life, and the worry, and you might turn suddenly. (Bill)*

*Tomorrow something might appear where I end up completely paralysed, where I won't be able to walk at all. It's something that I don't know. (Bill)*

Anthony's anxiety appeared to extend to his experiences with stress, or when hearing about the misfortune of others in his social network, such as his family and friends:

*I have it [worry] when I have a little stress, in other words, something troubles me, or I learnt something from a friend, from a member of my family, for one problem or another, or something goes wrong with my children. It's from those that I become easily troubled and I say, "It's enough that I am ill, not him as well." (Anthony)*

Depression following illness, which Bill perceived to be sadness, had consequences for him and his family. Bill also experienced other emotional responses, such as anger, in relation to the adverse impact of his illness (end-stage kidney disease) on his roles as spouse, parent, and father, or *nikokiris* in Greek (Greek Care, 2013d):

*When a person's body becomes ill, whatever that is, it's a little serious. Psychologically, it causes sadness. You don't want to go anywhere, you don't want to move, you don't want to eat, your child or wife talks to you, you become abrupt...because we weren't the same before we became ill, we were people who worked, we looked after our children, our families, our houses, whatever, but now, when you become ill, you can't do anything. (Bill)*

Furthermore, Bill believed that it was not possible to experience happiness following illness, and that nothing could be gained from illness experience:

*Whoever says that he is happy in life when he is ill, he'll tell a lie. (Bill)*

In summary, there were psychological consequences, such as experiencing cravings and dealing with restrictions to diet and fluid intake, which had the potential to affect coping procedures and illness outcomes if not managed properly. Other psychological consequence included reminders of illness, as well as emotional responses to illness, particularly frustration, sadness, depression, and anxiety.

***The social consequences of illness: Concerns about others' reactions.*** One participant perceived the importance of maintaining Greek cultural values, despite the potential risk to his own health. Anthony strongly believed in the importance of accepting Greek hospitality, or *filoxenia* in Greek, (Greek Care, 2013g) to avoid embarrassment, which also appeared to override his awareness of the negative consequences related to his increased sugar intake on his blood sugar levels:

*I am a person [who] always falls into the wrong, no matter how careful I am. I can't go to a table and sit, for you to offer me something and for me to say I don't eat it or I don't drink it because I have sugar. I'm embarrassed to say it and, forgetting that I'm not okay, I bite...those they offer you, a sweet on a teaspoon, I want it straight away, I crave it! The sugar asks for sugar, the diabetic always asks for sugar, and that's where I cop it, that happens.*  
*(Anthony)*



Furthermore, Anthony's ability to resist sweets, in order to avoid illness consequences, appeared to depend on the degree of familiarity of the people that he socialises with:

*When there is a familiar face that I recognise, I say, "You understand that I like it but it doesn't like me." I don't want it, but when I sometimes go to a table with people who are strangers to me, I embarrass him and how will he take it? (Anthony)*

Anthony may have also used hospitality as an excuse to override his self-control in order to satisfy his craving. Bill's illness appeared to have social consequences, which also included valued cultural influences associated with Greek hospitality (Greek Care, 2013g). For instance, as a result of his dietary restrictions, Bill's belief was that he needed to avoid the hospitality associated with Greek social interactions because he perceived himself as being responsible for making others anxious as a result of his illness. The illness thus impacted on his ability to smoothly enact a valued cultural role associated with Greek hospitality:

*It's affected me a lot because I go to a house for a visit. They say, "Bill, what will you drink, what can we serve you?" I want to drink a glass of beer, to drink a glass of water, I can't, and I avoid going for a visit because I notice that I make those people worry [about me]. (Bill)*

***The social consequences of illness: Social comparison.*** Social comparison was another consequence of illness experienced by several participants. Peter

compared his illness outcome with his best man, who he believed had a better illness outcome (upward comparison). An upward comparison of illness can have either a positive or negative effect on wellbeing (Buunk et al., 1990). In Peter's case, his upward social comparison appeared to have a negative influence in relation to how he perceived his own health and age in comparison to his best man:

*I said to him, "You'll surpass all of it because you are better than me. You came out better, and younger. You escaped it earlier." Those are what offend us. He'll get over it. I told my best man, "If I was like you, good." (Peter)*

Likewise, Spiro's upward comparison with healthy people in general appeared to highlight a negative quality of life as a consequence of his illness, which also emphasised an emotional element of fear:

*It affected [me] because you can't do that which a healthy person can do. The healthy person jumps, dances, drinks, does, says his words, goes on trips wherever he wants. How can I make the trips that I want? I'm scared. (Spiro)*

On the other hand, Anthony's downward comparison with a club member, who he perceived as having a worse condition than himself, appeared to improve his mood. However, this may have also contributed to a false sense of wellbeing that acted as a diversion from the reality of his illness:

*Sometimes I feel good when I see others [laughing]. I don't wish anyone to feel bad, but it relaxes me... I feel good when he says to me, "Oh, I'm going*

*to the toilet again”, and I say to myself, “Five minutes ago he was there, the same thing again! What’s happening to that person?”, and I say, “I sit here all this time and I don’t” [laughing]. (Anthony)*

***Qualitative observations of participants’ perceived health status (RAND SF-36) item responses in relation to health comparisons.*** RAND 36-Item Health Survey 1.0 Questionnaire (RAND SF-36) item responses regarding participants’ perceived health status in relation to health comparisons with others are presented in Table 3. Most of the participants’ responses appeared to correspond with their beliefs that emerged during interviewing. For example, Harry’s responses appeared to be congruent with his beliefs that his illnesses were not serious and were managed through medication, as well as a display of courage. Although Anthony’s ability to control his illness appeared to be tentative, his responses suggested that he appeared to view his health to be equal to others, congruent with his views regarding his illness through social comparison, as evident in the excerpt above. However, Peter’s response regarding his health, compared to others, was unexpected given his belief that he was as healthy as the interviewer, and his ‘wish’ for others to be as healthy as himself:

*I see myself extremely healthy like yourself now, but I know that I am pale, but I feel very well like you. No difference, psychologically. Whatever there was has passed. Nothing can be repaired! Since it’s not repairable, it’s like that. I feel like you. (Peter)*

*I wish all the cardiac people to be excellent like me. I really mean that. All those operated on to feel like me. (Peter)*

Table 3

*Participant Item Descriptions and Responses From the RAND 36-Item Health Survey 1.0 Questionnaire (RAND SF-36) in Relation to Health Comparisons With Others*

Participant <sup>a</sup>	RAND SF-36 item descriptions and responses	
	I seem to get sick a little easier than other people	I am as health as anybody I know
Spiro	Definitely true	Definitely false
Harry	Definitely false	Definitely true
Gerry	Mostly true	(did not respond)
Michael	Don't know	Definitely false
Bill	Definitely true	Mostly false
Anthony	Definitely false	Mostly true
Peter	Definitely false	Mostly false

<sup>a</sup>Pseudonym

***The social consequences of illness: Non-disclosure.*** Several participants believed in not disclosing their illness during social interactions to avoid the stigma of chronic illness (Joachim & Acorn, 2000), and because of their concern about the psychological effects of illness on others. Spiro believed that it was important for him to hide his illness in order to avoid stigma, and feelings of low self-worth:

*I never speak about myself. When I am with other people, I don't behave as though I'm ill. I don't want them to feel sorry for me. I behave as if I am very healthy, as though I don't have anything. I laugh and talk. I try. If another*

*person feels sorry for you, you are finished. I want them to see me strong! That's how I am. Nothing affects me at all. I have made up my mind that I don't want to drop my head at all. I want to hold my head up high. I appear as if I'm not ill. (Spiro)*

Anthony also believed in not disclosing his illness in social interactions because of his perceived concern about creating anxiety in others. However, his concerns about negative reactions from others may have also influenced his decision not to disclose his illness (Joachim & Acorn, 2000):

*With friends and relatives, of the many that don't know, I don't tell them anything. The person I am [with them] is the person I want to remain. It's another matter if they find out about it. Those that know already know. Those that don't know will not learn about it. I will not say anything to anyone. I don't like to worry them about my illness. Maybe they'll get annoyed and they tell you, "We got our own, you keep them for yourself." I have learnt to be sincere, to not tell each person what I have. (Anthony)*

Anthony also believed in the importance of presenting a positive self-image in the presence of his family because of his perceived concerns about the effects that a negative self-image may have on them:

*So that I am not affected by the idea that because I am ill, I make the rest ill...I try to always be a little firm, to have a profile where I display happy, even if I'm not happy. (Anthony)*

In summary, regarding social consequences, there was dissonance between participants' illness management and cultural values (Greek hospitality) as well as social influences associated with being 'strong', taking care of, and being concerned about the reactions of others, which could potentially have serious consequences for appropriate management of their illness. There were also upward and downward social comparisons of illness, with what appeared to be negative consequences on perceptions of health, affect, and quality of life for upward comparisons (Buunk et al., 1990). Participants did not disclose their illness because of the fear of stigma, and the need to preserve self-esteem and improve self-worth.

Participants' views regarding serious illness consequences could influence their willingness and ability to control their illness and impact on their self-efficacy beliefs, coping procedures, and illness outcomes.

**Illness Cure / Controllability.** This illness representation relates to participants' views regarding cure and controllability of their illness (Scharloo & Kaptein, 1997). The themes of treatment control comprised of a number of sub-themes, including reliance on medical professionals and reliance on medical equipment. The themes of personal control also comprised of several sub-themes, including lifestyle behaviour and self-control.

***Treatment control: Reliance on medical professionals.*** There was a strong belief by a number of participants in the importance of medical professionals to help them control their illness:

*The only treatment I follow is the doctors'. They know. They tell me what I have to do. (Anthony)*

*You'll go to the doctor. He'll give you the medication. What else do you do?*

*(Harry)*

Harry held a strong belief in a reliance on his doctor, along with the use of medication, for managing his numerous chronic conditions, which appeared to contribute to his perception of self-control over his illness:

*When the illness occurs, you don't know what you have. When you go to the doctor and you confirm and have an examination on what you have, and they give you the appropriate medication, you become calm, you face the illness. I don't have any problems with the illnesses, now I take the tablets. (Harry)*

Spiro believed in the medical profession, to whom he entrusted management of his illness:

*I believe in professionally qualified people, in doctors. I believe first in the doctors and then God. I am very happy with those things that they say and do with me. (Spiro)*

However, because of his respect for the medical profession, rather than challenging his doctor's authority, Spiro believed in complying with his doctor's instructions to avoid embarrassing himself and disrespecting his doctor:

*I believe in doctors. My reactions were to do whatever the doctors told me to*

*do because if you don't do what they say, you shouldn't go to the doctors at all. What do I do? You have to tell me and whatever you say, I have to do. If I don't do it, I become embarrassed and I make fun of you. (Spiro)*

Participants' beliefs in medical professionals may have also represented, in some cases, an attempt to transfer responsibility for their illness management to their doctors.

***Treatment control: Reliance on medical equipment.*** A reliance on computerised equipment was perceived by one participant to be critical for the control and survival of his illness. Bill believed that his computerised haemodialysis had become a critical piece of equipment to help him control his illness, as well as to help him continue to live, given the state of his kidneys and his advanced age:

*That [haemodialysis] is the therapy. Nothing else is suitable because for them to give me kidneys, it's my age now. It can't take them. They don't do that now, and even if they did, they're useless. The body would not accept them, because there is no strength. (Bill)*

Despite his anxieties about his illness, including his concerns about an uncertain future, as evident in other excerpts, Bill perceived that his computerised haemodialysis allowed him to feel somewhat more settled regarding his ability to control his illness:

*Those methods exist, the machines exist, the cleansing exists, and life becomes a bit smoother. (Bill)*



In summary, participants highlighted the importance of medical professionals and medication for the control of their illness. Medical professionals were invested with expertise and authority and expected to assume responsibility for the management and treatment of illness by some of the participants. One participant (Bill) also viewed a reliance on medical equipment to be critical for the control of his illness.

***Personal control: Lifestyle behaviour.*** Several participants perceived that they could control their illness through lifestyle changes, such as a healthy diet and exercise. Peter believed that exercise, along with distraction, had helped him to control his illness by reducing his stress level:

*Exercise, whenever you can, the more the better. Even two times [a day] is good. To get rid of emotionally whatever harmful and terrible and difficult problems that are present. (Peter)*

But Peter also believed that it was important to avoid certain forms of physical exertion, such as lifting heavy objects. However, information on coronary artery bypass surgery indicates full recovery occurs after three or four months (Farlex, 2013). Yet, Peter had his surgery 15 years prior to interviewing. It may be that Peter believed he needed to maintain a cautious approach regarding any form of strenuous physical exertion in order to avoid stress and the possibility of re-experiencing a heart condition:

*You do those that you can, whatever you can. You can't, you leave it there. There is no nobody's around and he lifts it. If the build is not there, finish, stop. If you can't, the heart is the heart! It beats and walks, as far as it endures. You're tired, [then] you rest and you finish. (Peter)*

Along with exercise, Peter also believed that eating a healthy diet, including moderate servings, was important for the control of his illness. However, Peter had also experienced difficulty with maintaining a healthy weight range, which suggested that his behaviour did not appear to match his beliefs in this area:

*It's good for a person not to eat a lot, to eat healthy [foods], and to stand, in other words, to wander, and work. Health is those basic things. Not only green vegetable food, to eat a variety of everything, and to drink. (Peter)*

Anthony appeared to display a tentative belief regarding his ability to control his illness through self-monitoring and lifestyle changes:

*I myself have to understand that I have it, I need to monitor them, and that it needs a lot of attention in anything I eat, in anything I drink. (Anthony)*

Anthony also believed that a healthy diet helped control his illness (diabetes). However, he also perceived that eating a healthy diet was not always pleasurable, which may have contributed to him engaging in unhealthy eating habits and complicating his ability to control his illness:

*Another says, “I don’t have iron in my body” and he says, “Take lentil soup, take lettuce, take spinach, take those yellow [squash].” It is good for the sugar, it cuts it for that day, it reduces it, but you can’t do that all the time! There are many things that help the blood pressure. You can’t eat green vegetables every day. (Anthony)*

**Personal control: Self-control.** The importance of self-control, which included the regulation of thoughts and emotions, was highlighted by a few participants. Anthony believed that he could manage his illness, and feel calmer in the process, by following his treatment regimen, including medication adherence and self-monitoring to try and stabilise his blood sugar levels to the best of his ability:

*It [illness] troubles you, but that trouble becomes milder, it becomes more normalised when you know what you have to do, and you follow the rules, the regulations that they say over here, and the medication that the doctor will give you, so that you can become established in the program that you follow... I cannot forget the illness, therefore you have to do something, you have to correct it. If it can’t be corrected completely, at least keep it at the regular, at the medium level, as they say, up and down, so that you know where you stand. (Anthony)*

Anthony also believed that it was important for him to avoid negative thoughts about his illness in order to try and alleviate his anxiety, which appeared to be potentially problematic with negative consequences for him:

*To make life easier, calmer so that your mind does not race and you say, “Oh, what will happen tomorrow? It’s my last day tomorrow.” That thing can’t be corrected, that can’t be repaired, to worry more. You have to bring one problem [around], and say, “Even though I’m ill, even though I think about it, so I won’t think about it”, so that you can find a calmness within yourself, peace. The worry is the worst of all, there is nothing worse. When you have pressure, it’s like having an extra illness. Something pressures you, something bothers you, you think about it, you re-think about it, and it makes you become more sick. (Anthony)*

In summary, participants considered changes in lifestyle behaviour (exercise, diet), self-control and self-monitoring, and emotional regulation, important for the control of their illness.

In conclusion, illness was commonly attributed to external factors, such as stressful life events, heredity, and deterioration of bodily organs, moderated by age (age-illness rule) (Martin et al., 2003). Beliefs were consistent with the biomedical view of illness (Yuill et al., 2010) rather than based on participants’ culture or religion (e.g. evil eye, act of God). External attributions for the cause of illness could potentially influence coping procedures and illness outcomes in accordance with the degree of responsibility assumed for the cause of illness.

There were serious physical consequences for participants, such as a reliance on life sustaining equipment. Other physical consequences, such as limitations to physical exertion and reduced strength, imposed restrictions on quality of life. Age and other co-morbid conditions also appeared to influence perceptions of reduced strength with illness. At other times, age was attributed to be the cause of illness (age-

illness rule) (Martin et al., 2003). There were also psychological consequences, such as experiencing cravings and managing restrictions (diet and fluid intake), which had the potential to affect coping procedures and illness outcomes if not managed properly. Other psychological consequences included reminders of illness, as well as emotional responses to illness, more commonly depression and anxiety. Social encounters also impacted, particularly concerns about the reactions of others to the illness and its restrictions, creating dissonance between cultural values (Greek hospitality) and self-control, and potentially impacting on illness management. Other social consequences included upward and downward social comparisons of illness (Buunk et al., 1990), and non-disclosure of illness because of fear of stigma. Participants' views regarding serious illness consequences could influence their willingness and ability to control their illness, and impact on their self-efficacy beliefs, coping procedures, and illness outcomes.

The role of medical professionals, along with a reliance on medication, was viewed as important for the control of illness. Medical professionals were invested with expertise and authority and were expected to assume responsibility for the management and treatment of illness by some of the participants. One participant (Bill) viewed his reliance on medical equipment to be critical for the control of his illness. Changes in lifestyle behaviour (exercise, diet), self-control and self-monitoring, and emotional regulation, were also considered important by participants for the control of their illness.

## **Chapter 8**

### **Common Sense Model (CSM) Coping Procedure Themes and Psychosocial Themes**

Chapter 7 presented themes directly related to the Common Sense Model (CSM) on individuals' perceptions of their chronic illness (illness representations). The present chapter will present themes concerning coping procedures, which have been derived from thematic analysis of interviews with participants and are shaped by the CSM illness representations. Thematic analysis of coping procedures for participants in the present study will examine the strategies undertaken by participants to cope (or not) with their illness. This chapter will also present psychological and social (psychosocial) themes, as well as cultural aspects relating to participants' adjustment to chronic illness, which have been derived from thematic analysis of interviews with participants and are not directly related to the CSM. Thematic analysis of participants' adjustment to their chronic illness in the present study will examine the processes by which participants adjust (or not) to their chronic illness as well as their outcomes. Finally, this chapter will present social aspects of participants' experience of chronic illness, not directly related to the CSM. Thematic analysis of social influences in the present study will examine the influence of social support and social interaction on their chronic illness experience. Excerpts from the interview transcripts are presented to illustrate each of the themes.

#### **Common Sense Model (CSM) Coping Procedure Themes**

The following section presents themes based on coping procedures from interview material, shaped by illness representations of the CSM (Leventhal et al., 2001). Coping procedures are the actions (behavioural and cognitive) undertaken by

individuals to attain goals, such as to improve their health or to cure, control, or rehabilitate from illness (Leventhal, Leventhal, & Contrada, 1998). Coping procedures have been shown to be related to illness representations (Hagger & Orbell, 2003; Rutter & Rutter, 2002), and to mediate relationships between illness representations and illness outcomes (Rutter & Rutter, 2002). The coping procedure themes are presented in Table 4. Excerpts from interview transcripts are presented to illustrate each of the themes.

Table 4

*Coping Procedure Themes Relating to the Common-Sense Model (CSM)*

Themes	Subthemes
Coping Procedures	Use of medical services
	Physical activity
	Self-control

**Use of medical services.** Consistent with their beliefs in medical professionals for the control of their illness, participants coped with their illness by seeking medical help. Spiro's compliance with his doctors' advice was consistent with his beliefs regarding the importance of his doctors for the control of his illness (diabetes, kidneys disease):

*I do whatever the doctors tell me to do. I don't do anything of my own accord. (Spiro)*

Furthermore, he believed that that his doctors helped him to function, enabling him to avoid ruminating about his illness:

*To the doctor as much as I can so that I can do more things in order to be steady so that I don't sit and think about how ill I am. (Spiro)*

Anthony appeared to have a good command of the English language, which enabled him to access English Encyclopaedias and gain knowledge regarding the symptoms and label for his illness. After identifying specific symptoms of his illness (diabetes), Anthony engaged in prompt help seeking behaviour:

*I have read it. I have a row of encyclopaedias. I discovered it [diabetes] myself and I went straight to the doctor. Those are the symptoms. I went on my own and told them what I had. (Anthony)*

Anthony's identification of his illness (diabetes), which he claims to have been "very lucky" to discover, also contributed to his insistence in obtaining medical help:

*I was very lucky that I detected it myself. I went to the hospital...I told him "I would like to see a doctor because I'm a sugar diabetic...They did the first test and they weren't quite sure because it didn't show that much...They told me, "The next day." I told him, "The next day I'm not coming for another test, I'll come so you can keep me inside and fix me up", and I went 9 o'clock in the morning with my pyjamas [laughing], with the facilities that I had. (Anthony)*



On the other hand, despite his commitment to regular check-ups, Anthony claimed that he wanted to “make them happy”, suggesting a need to please his medical team:

*Every three months, or every six months, I have a cardiologist. I have kidney and other examinations for ultrasounds, etc., in the barrel [MRI scanner], wherever they send me. I am an outward patient all the time. They work. I also work with the running, to make them happy. (Anthony)*

Harry’s advanced age appeared to reinforce his reliance on doctors and his adherence to medication to manage his multiple illnesses (glaucoma, gout, prostate cancer, chronic stomach condition [intestinal inflammation]):

*I don’t care. I take the tablets and wherever it leads. The years are gone, never mind. Better they look after me. (Harry)*

A few participants relied on medical equipment, which also enabled them to live. Michael was committed to daily oxygen therapy because he was aware that he could not survive without it (serious consequences):

*I take oxygen three to four times a day [with] the oxygen machine. (Michael)*

Bill was also committed to his daily haemodialysis because he was aware that he could not survive more than a few days without it (serious consequences), and

because he believed that there was no other viable option available to him (controllability):

*We do what they tell us [to do]. I do the treatment now with the bags, with the machine. It does the provision for the kidneys and, in the morning, it finishes and I start the day as normal again. (Bill)*

In summary, participants coped with illness, in part, by relying on medical professionals. Spiro's reliance on his doctors had helped him to function and avoid ruminating about his illness (diabetes). Anthony, who insisted on obtaining medical help after initially identifying his illness (diabetes), participated in medical check-ups to please his medical team. Harry reinforced his reliance on medical professionals, who were invested with expertise and authority, and his adherence to medication with age. Participants also coped with illness, in part, by relying on medical equipment, such as daily oxygen therapy (Michael) and daily haemodialysis (Bill), which also enabled them to live.

**Physical activity.** Several participants relied on exercise to manage their illness. Spiro's claim that he could "see and walk well and that's okay" indicated a positive appraisal of exercise for his illness (diabetes, kidney disease). He also appeared committed to his exercise to try and prevent any further deterioration in his illness:

*I exercise to minimize it so I don't lose my sight or my legs. It's a bad illness and so I walk. I've tried until now. I can see and walk well and that's okay. (Spiro)*

Consistent with his beliefs regarding the control of his illness (coronary artery disease), Peter used exercise (walking alone) combined with visual imagery to improve his mood and reduce his stress:

*[I become] irritated and I walk. I don't think about the irritation on the road. I see a beautiful woman on the road, I undress her, in fantasy, and I play games...You create happy again with yourself. (Peter)*

In summary, there was a positive appraisal of physical activity (exercise) for one participant (Spiro), who believed that exercise prevented further deterioration of his illness (diabetes). Exercise, combined with visual imagery, helped to improve mood and reduce stress for another participant (Peter), which was consistent with his beliefs regarding the control of his illness (coronary artery disease).

**Self-control.** Participants' ability to manage their illness through self-control varied. Bill's commitment to closely monitor and estimate his daily fluid intake was motivated by his awareness of the consequences of exceeding his daily limit:

*If I drink, for example, a coffee in the morning, or I drink a glass of milk, whatever, you have to estimate that, now, for example, I ate a little yoghurt, how much water is there in a cup of yoghurt? You have to think about those things. You'll eat some jelly, for example, how much water has the jelly got inside it, and you have to estimate that the total is one litre, the fluids it has, because if I take on more fluid than that, I'll have trouble. (Bill)*

Anthony's ability to manage his diabetes was complicated by his inability to moderate his consumption of certain foods, such as carbohydrates (pasta):

*I love pasta. I can have three, four plates of pasta, which is the wrong thing.*

*I like to eat vegetables, but I can't eat vegetables every day. (Anthony)*

Despite a previously successful five year period of controlling his diabetes through diet alone, Anthony disclosed that he succumbed to diabetes again after giving in to his temptation for food and alcohol. He chose to ignore his reported awareness of his habits because of the enjoyment that he derived from them, which he also blamed on his youth. He waited until it was pointed out to him by his GP, when it was too late, which resulted in a reinstatement of his medication and insulin. His self-admission that his oral cravings obstruct his ability to "stop the insulin tomorrow" indicates a resignation in his ability to successfully manage his diabetes:

*It stopped once for five years, without the insulin, and I was doing very well, but I'm a person who grabs, and I returned back to where I started. The sugar was there, but all was going well without the medication! Only with the diet, but it returned again because I started pinching. I didn't only eat, I drank. I like the drink...I knew what I was doing...I held. I was younger. It was actually a big sacrifice, for me. I didn't even see it [coming]. I was going to the GP...and he noticed that I was doing something wrong, and I returned again to the insulin. I can stop the insulin tomorrow if I wanted to, but it's that I want to eat, I can't have both, [especially] now that I don't*

*walk, I don't move, I don't work. My head goes to the food. I want to open the fridge, to grab what's inside. Many I can't grab, but I grab them anyway. A little, I grab, that's the truth. I can't hide it. (Anthony)*

In contrast with his ability to manage his stress through exercise, and despite his beliefs that a moderate and healthy diet is needed for the control of his illness (coronary artery disease), Peter found it difficult to manage his weight:

*The weight has gone to hell, for me. I can't easily control it. (Peter)*

Despite claiming to have “repaired” his diabetes “to a reasonable extent” and to “maintain it where necessary”, Anthony reduced his blood glucose monitoring to once a day because he perceived that it had a negative impact on him. He did not disclose the nature of the negative impact:

*I repaired it to a reasonable extent, and from then until now, I maintain it where necessary. (Anthony)*

*I used to do it three times a day, and then I cut it to two. Now, I cut it to one, my test every morning. I can't be bothered because I know the feeling, what I feel in the afternoon. (Anthony)*

By reducing the frequency of his blood glucose monitoring, Anthony was perhaps complicating his own and his doctor's ability to respond to changes in the management of his diabetes, including irregular blood glucose levels, such as

hypoglycaemia (low blood sugar) and hyperglycaemia (high blood sugar) (Diabetes Australia, 2013).

A number of participants attempted to cope with their illness through other means, such as regulating emotions, distraction, relaxation, and displaying courage. Michael used distraction (music) to reduce his anxiety and depression following recollections of previous stressful life events (loss of businesses and house). Despite their occurrence many years ago, his coping strategy had not enabled him to come to terms with his losses:

*If I think about anything bad in my mind, I put the record on and it plays, and I try and forget that old, the bad that I was remembering initially, with the good from the record that's playing. (Michael)*

Unlike his difficulty in regulating his blood glucose levels by moderating his diet and sugar cravings, Anthony appeared focussed on managing his anxiety and stress to prevent further deterioration in his illness (diabetes):

*It has affected me many times, but no matter how much it affects me, because I know what I have, I am careful not to worry so that I don't become more ill. (Anthony)*

*The only thing I do is to go and lock myself inside my room. Nice. Quiet... Whatever bothers me, I will relax. I sit comfortable. I don't feel anything. Then five, six minutes later, I feel good. (Anthony)*

Despite claiming to experience occasional “worries” about his illness, Harry’s reliance on composure and courage had helped him to live with his illness and contain his anxieties:

*However you look at it, it worries you sometimes but you think about composure at the beginning because when you surrender and you worry, you die. You take courage in life. That is the best doctor. If you become disappointed, you’re finished. (Harry)*

One participant perceived that he could help control his illness by managing his level of stress. Bill believed in the importance of self-talk in helping him moderate his stress:

*I might have it for a little while, and then it will leave, because I tell myself nothing can come of it. (Bill)*

In summary, participants’ ability to manage their illness through self-control varied. Bill’s motivation to monitor and estimate his daily diet and fluid intake for his illness (end-stage kidney disease) helped him to avoid serious consequences. Anthony resigned to his inability to manage his diet, which adversely impacted on his blood glucose levels and his diabetes management. This was despite his previously successful five year period of controlling his diabetes through diet alone, as well as his awareness of the need for caution with his dietary intake. Moreover, unlike his ability to manage his stress through exercise, Peter was unable to control his weight which was discordant with his belief in a moderate and healthy diet to control illness.

Anthony's self-imposed reduction in the frequency of his blood glucose monitoring may have complicated his ability to respond to changes in blood glucose levels (hypoglycaemia, hyperglycaemia) (Diabetes Australia, 2013).

Participants also coped with illness by relying on other initiatives, such as regulating emotions, distraction, relaxation, displaying courage, and self-talk. Michael's reliance on distraction (music) to cope with recollections of previous stressful life events (loss of business and house) had not helped him to accept his losses. Anthony focussed on regulating his anxiety and stress to prevent further deterioration in his illness (diabetes). In contrast, a reliance on composure and courage helped Harry to live with his illness (glaucoma, gout, prostate cancer, chronic stomach condition) and contain his anxieties. Bill reverted to a cognitive (self-talk) coping strategy to help manage stress associated with his illness.

In conclusion, participants coped with illness by relying on medical professionals. One participant's (Spiro) reliance on his doctors had helped him to function and avoid ruminating about his illness (diabetes, kidney disease). Another participant (Anthony), who insisted on obtaining medical help after initially identifying his illness (diabetes), participated in medical check-ups to please his medical team. Harry reinforced his reliance on medical professionals, who were invested with expertise and authority, and his adherence to medication with age. Participants also coped with illness by relying on medical equipment, such as daily oxygen therapy (Michael) and daily haemodialysis (Bill), which also enabled them to live.

Participants also coped with illness by engaging in physical activity. Spiro's positive appraisal of physical activity to manage his illness (diabetes) appeared to contribute to his belief that exercise also prevented further deterioration of his illness.



Exercise, combined with visual imagery, helped to improve Peter's mood and reduce his stress, which was consistent with his beliefs regarding the control of his illness (coronary artery disease). On the other hand, participants' ability to manage their illness through self-control varied. To avoid serious consequences, Bill was motivated to monitor and estimate his daily diet and fluid intake for his illness (end-stage kidney disease). Despite Anthony's previously successful five year period of controlling his diabetes through diet alone, and despite being aware of the need for caution with his dietary intake, he became resigned to his inability to manage his diet, which adversely impacted on his blood glucose levels and diabetes management. Moreover, despite Peter's belief in a moderate and healthy diet to control illness, and unlike his ability to manage his stress through exercise, he could not control his weight. Anthony's ability to respond to changes in blood glucose levels (hypoglycaemia, hyperglycaemia) was complicated by a self-imposed reduction in the frequency of his blood glucose monitoring (Diabetes Australia, 2013). Other strategies participants used to cope with illness were regulating emotions, distraction, relaxation, and displaying courage. Michael relied on music as a coping strategy to distract him from recollections of previous stressful life events (loss of businesses and house), which he had not reconciled. Anthony's focus was on regulating his anxiety and stress to prevent further deterioration in his illness (diabetes). Harry's reliance on composure and courage appeared to help him live with his illnesses (glaucoma, gout, prostate cancer, chronic stomach condition) and contain his anxieties. Bill's cognitive (self-talk) coping strategy helped him to manage stress associated with his illness.

### **Psychosocial Themes**

The following section presents themes relating to the processes and outcomes of participants' psychosocial adjustment to their chronic illness, as well as themes

relating to the influence of social and medical support and social interaction on chronic illness. According to Sharpe and Curran (2006), adjustment is the process of preserving a positive view of the self and the world in the presence of a health problem, including chronic illness. Helpful illness representations can lead to adaptive psychological functioning, whilst unhelpful illness representations require other ways to integrate illness representations into adaptive views of the self and the world (Sharpe & Curran, 2006). One way in which individuals may facilitate adjustment to their chronic illness is through a search for meaning by incorporating their chronic illness (a life changing event) into their pre-existing beliefs and pursuing goals that provide a purpose in their lives despite the restrictions imposed by their illness (Park & Folkman, 1997). Successfully negotiating the process of adjustment, by finding meaning, can lead to positive outcomes, such as an appreciation of life. However, negative outcomes can also ensue from individuals' search for meaning, resulting in adjustment difficulties (Park & Folkman, 1997; Sharpe & Curran, 2006), such as depression or loss of purpose, and can also result in altered self-identities (Charmaz, 1995b).

Individuals' supportive social network ties may also enhance health by providing basic human needs, such as companionship, intimacy, a sense of belonging, and a reassurance of self-worth. Moreover, social support may contribute to individuals' perceptions of personal control of their chronic illness by reducing uncertainty or unpredictability (Heany & Israel, 2008). Companionship may also facilitate positive mental health for individuals with chronic illness, or may be perceived as unnecessary or intrusive (Rook, 1990). Themes relating to psychosocial adjustment to chronic illness and social influences are presented in Table 5. Excerpts from interview transcripts are presented to illustrate each of the themes.

Table 5

*Themes Relating to Participants' Psychosocial Adjustment to Chronic Illness and Social Influences on Participants' Chronic Illness Experience*

Themes
Finding meaning
Adapting to illness
Finding Benefits
Finding a Purpose
Role of support: Medical and social
Importance of social interaction

**Finding meaning.** The search for meaning was encountered and managed in various ways by participants in this study. Bill appeared to find it difficult, initially, to make sense of his illness, including coming to terms with an unexpected change in his familial and masculine role that ensued with illness. However, he appeared to eventually overcome his initial uncertainty by learning to adapt to the daily requirements of his illness, which also appeared to help him reconcile to his illness:

*I have that stress and ask myself, "Why should this happen to me?" It affects me, this thing. It troubles me a lot...because I was active once, in my jobs, but now I can't do those things. (Bill)*

*I can't say, "Oh, what happened to me, oh, why!" That's serious, because you become even worse. Just take it psychologically and take one day at a time. (Bill)*

Despite his initial struggle in his search for meaning following illness, including self-criticism for his perceived comparative vulnerability, Anthony also appeared to eventually reconcile to his illness:

*The only thing I thought about when I discovered it, which I couldn't digest, I couldn't understand, is why it should happen to me? I asked myself that question, why me and not someone else? That's a mistake. I should have taken it like other people take it and say, "It fell to me, I'll fight it, [and] I'll keep it, whatever I can do." I should have done that from the beginning. When I started to understand it myself, I said, "I have it, I have to fight it." It happened. You can't do anything about it. It's like getting a bottle of milk. It spills. You can't gather it and put it back. [It's] exactly the same. (Anthony)*

Anthony also held a strong cultural belief that his illness was attributable to destiny. In the Greek language, destiny is referred to as *γραφό*, or "something that is written", and is commonly known in the Greek culture as "something that must happen to a person because it is predetermined and cannot not occur" (Avgoulas & Fanany, 2012, p. 85). After initially questioning why he became ill, Anthony began to view his illness as something that was predetermined:

*That's written in the books...That was on the cards to happen! It's in the program of each person's life to happen. (Anthony)*

Spiro appeared to come to terms with his illness by attributing it to his own luck, or *τύχη* in Greek. In the Greek culture, a person with a serious illness or an

incurable disease is said to be experiencing bad *τύχη* (Greek Care, 2013a). Despite claiming to view it as “a bad dream”, he goes on to express resignation about his ‘unlucky’ illness. He uses his perceived accomplishments to deny and minimize his envy of other healthy individuals:

*I view it as one bad dream. I am yet to believe that it happened to me, but it is a fact, it is so. It happened... Other people are not to blame for my being ill. Why should I be jealous of people who are healthy? That's my luck, the rest, alright, happy. Everybody's happy. I have good kids, I have good grandkids, I have made good friends, and I have made best men/Godfathers. I have made very many things. All this is good (Spiro).*

Michael found it difficult to come to terms with his illness, which was reinforced by a sense of helplessness:

*A person lays out his plan, how this illness came upon me and did not go elsewhere, and it came to me. That's what I think about, but I can't do anything about it. It's contagious. (Michael)*

*Compared to being well and becoming suddenly ill, from that I submitted to. Indeed, that is hard for me to swallow in my life. (Michael)*

In summary, participants' search for meaning, and their process of coming to terms with their illness, varied. Participants became accustomed to illness, learnt to face illness, and resorted to cultural attributions ('luck', 'fate'). However, one

participant (Michael) was unable to come to terms with his illness, instead expressing a sense of helplessness.

**Adapting to illness.** “Adaptation implies the reorganisation and acceptance of self so that there is a meaning and purpose to live that goes beyond the limitations imposed by the illness” (White, Richter, & Fry, 1992, p. 211). Adaptation through acceptance was also evident in the present study’s participants. Spiro’s belief that his illness was due to fate (inevitable), or *μοιραίο* in Greek (Pring, 2000), appeared to serve as a protective factor by helping him to accept, rather than fight the reality of his condition:

*I have accepted that [illness] as inevitable and it doesn’t affect me at all now...I don’t think about it. I don’t want to think about it. I don’t like to think about I’m sick. Why should I think about? Nothing to win. My aim is to be happy. (Spiro)*

Peter’s pragmatic approach towards his illness appeared to have enabled him to adapt constructively to his illness, including physical constraints imposed by his illness:

*You took it like as though they took your hand and you’re left with one hand. What can you do? Whatever you can, you’ll do. You’ll manage. It’s physiological. Nothing can be done! (Peter)*

However, Peter also appeared to be overly cautious about his physical limitations (exertion) long after coronary artery bypass surgery. Advanced age and a

strong belief in medication and the medical profession may have served as mediating factors influencing Harry's resigned attitude to his illness:

*Nothing has changed for me. It continues and nothing concerns me. I take the medication and however far it goes. (Harry)*

*Thank God. For the age I'm at, I'm well. The age I'm at now, what do you want me to be? (Harry)*

Several participants mentioned suicide, saying that this was not an option for them. Rejection of suicide appeared to provide motivation for them to adapt to the reality of their illness:

*[When] they said...I have to have a bypass, it offended me because you don't know if you'll remain alive with an operation like that. It offended us because we were operated on from nowhere, and since we had to be operated on, we ended up accepting that life. We'll do the required things straight. We ate it and we digested it. Well there isn't anything else. How? You'll go and commit suicide? Go and fall freely. (Peter)*

*I took it seriously [at first], but slowly, slowly, I got used to it. What could I do? I can't do anything else since there is no other path. What can I do now? Die, commit suicide? It won't happen. (Bill)*

Out of necessity, Bill adapted to his routinised daily haemodialysis treatment, recognising it to be an integral part of his life:

*I put on the machine, the night will pass. Tomorrow night I'll have the same thing [happen]. That's the everyday which becomes not only a big worry, but it also becomes a routine and you say [that] you accept it. (Bill)*

Furthermore, Bill's adaptation to a daily ritual of monitoring his dietary and fluid intake appeared to be motivated by his understanding of the serious consequences of not abiding by them:

*It bothers me, but what can I do? To eat it and it eat me? It won't happen. (Bill)*

In summary, participants' adaptation to illness was related to an acceptance of illness. Approaches used included a belief in 'fate.' One participant's (Peter) pragmatic approach enabled him to adapt constructively to his illness. Another participant's (Harry) resignation to his illness was mediated by age and a reliance on medical help. Adaptation to illness was also aided by a rejection of suicide and a necessity to habituate to treatment requirements.

**Finding benefits.** Finding realistic benefits from illness has been associated with emotional well-being and the possibility of long-term health benefits (Affleck & Tennen, 1996).



Several participants claimed to have benefited from their illness experience. There was an element of surprise in Anthony's good fortune in surviving his illness for so long, the benefit being his renewed appreciation of life:

*The only thing that I have gained, from the time I became ill until now, is that I am still living. That's the biggest goal that I have gotten out of it. To live that long, after all this sickness, is a great goal for me, better than anything! Life is sweet. (Anthony)*

Anthony also emphasised his relatively good quality of life, despite difficulties associated with the management of his illness, comparing his fortune at being able to provide Greek hospitality with the adverse circumstances of his impoverished countrymen:

*Better quality of life. A lot better. We don't miss anything. Even if we got a sickness, we declare we have everything. We lack nothing, and we are not embarrassed to invite a person to our home and tell him, "Sit and eat", whereas many people over there [Greece] don't have enough to eat. (Anthony)*

Some of the participants' beliefs that they had managed well, despite their illness, appeared to indicate satisfaction with their life achievements. Spiro also felt it was important for him to acknowledge his good fortune, which he attributed to God, which is common for his Greek generation (Avgoulas & Fanany, 2012):

*“In all this life, apart from the health, thank God,” I said, “I’m fine.” (Spiro)*

*Life now is a bit serious as a result of the illness, but still we get by. We’re progressing well. (Bill)*

In summary, benefits derived from illness included heightened appreciation of life, changing life-style to effect a better quality of life, positive evaluation of life achievements, and comparative evaluation of participants’ lives with people perceived to be less fortunate.

**Finding a purpose.** Most of the participants held beliefs in relation to their purpose in life, despite illness, related to the attainment of significant goals.

Anthony’s goal was to affirm life and to survive long enough to see child relatives attain developmental milestones:

*As much as you say that you’re ill, that you want to leave, you want to do, you want to show, there arrives a moment that you say... “I have to live, to see those children grow up, to see them perhaps one day to get married, even if I can’t walk, to go to the church, to see them happy.” Well, those will make me happy, to think about the good, not the bad. (Anthony)*

After reflecting on the brevity of human life, Spiro focussed on improving his friendships and familial connections:

*You have to view life from the positive side. We are here for a limited time...Nobody lives forever. The aim is to be good with the people you live*

*with, with your family, with your children, your friends. To not worry about other things. (Spiro)*

Despite questioning how long he had to live following his illness, Peter aspired to improve the quality of his remaining life:

*At the beginning, before the operation, the illness cuts you, in energy and in action, and you think, "How many more years will I live?", and that how you keep inside. It doesn't stop. Every time you go to do something, [you say] "What do I want to do [with that], to write a book, will I have enough time?" You say "Why don't you look at living well, with the final day, with the final moment, and live each moment well!" That is the connection. (Peter)*

On the other hand, the onset of Michael's illness had contributed to his depression, including multiple suicide attempts and feelings of worthlessness and despair:

*Many times I decided to end my life. I took tablets to commit suicide. My life was good before I became ill. After I became ill, my life was finished. I feel, like a finished person. I don't have a good mood for anything. There is no cure for me. There is no life. (Michael)*

In summary, participants' search for a purpose in life included goals to affirm life, to live and witness child relatives attain developmental milestones, to improve relationships with friends and family, and to live well for the remainder of

life. On the other hand, there was a loss of purpose in life for one participant (Michael) following illness.

**The role of support: Medical and social.** Several participants discussed the role of medical and social support in relation to their illness experience. Harry distinguished between medical support for his illness, provided by his doctor and his medication, and support from his social network, which was viewed as comforting and providing company:

*Now that I'm alone, if I'm not well, I call and some friend comes and we sit. You welcome people. [For] the illness, there is the doctor, the medication. You call your brother. What can he do? What can he help you with? Apart from a visit, what else do you want him to do? To examine you, what can he do? In a consoling way, we converse. They can't do anything else for you.*  
(Harry)

Spiro believed that it was the hospital's role to provide instrumental and medical support for his illness. He also acknowledged support from friends and family:

*I'll go to the hospital, I'll stay there, and the nurses and doctors will look after me. I don't want an expectation of my friend, or my brother, or my sister to look after me. That's why there are hospitals, so that they can look after me. My wife has helped me, my children have supported me. I also have many friends that have helped me. Everything else is ok. Thank God. I don't have any complaint.* (Spiro)

Anthony believed that social support, such as pleasant conversations, was equally therapeutic for his illness as medical support, such as medication:

*The whole thing is to take it within you, and think that that person, whether he provides me with medication, or whether he provides me with a good conversation, he wants to help me, in which case, it is good for me to listen to him. I don't want money! I want a good conversation! I want a practical medication, if he has it, as there are many which help the sugar. (Anthony)*

Furthermore, Anthony viewed conversations to be more beneficial and relevant in the support of his illness than financial support, which was also the case for Spiro:

*I never had any problem with money...It's more about if you happen to come by my house and talk and eat with me, tell me how you're going, that's the support. (Spiro)*

Anthony rejected the offer of external support (professional care) following his rehabilitation, believing that others needed it more than him. However, his claim that he preferred to be independent was discordant with his reliance on familial support to help him with his daily tasks:

*The bottom line is that nobody can offer me more than what my home can offer me. I've done the rehab for six months. They offered to fix my*

*bathroom, but I had already fixed them...They talked to me about bringing a nurse to bathe me. I said, "No, my wife will do it for me." I said, "Give her somewhere else where she is needed more than on me." I wouldn't accept it. They even offered to take me once a day for a cup of coffee, a special driver, to take me for a shopping or something. I told her, "No, I have my wife so many years. I have made her an expert behind the wheel. She will do everything for me, nobody else. If my wife's not here, I have my children. They come once a week. Somebody will take me." I wouldn't accept it because somebody else needs it more than me, not because I'm a proud of myself. I prefer to be independent. (Anthony)*

Peter rejected external support for his illness because of his concerns about stigma, and because he viewed himself as healthy and independent:

*It offends us when a person runs and gives a lot of support, because it shows you that you are unfortunate, and I avoid it and don't want a lot of it...Recognition, yes, but not support. It's like being a special, different person, the patient, and you're supported [by] the community. No! I am equal...Supports [are] things which show that you are ill, that you suffer from something and you need support. It shows that you are not healthy, you are ill. I feel good. (Peter)*

*Since I do everything, whatever I need, I do myself, I don't ask from anyone. (Peter)*

Anthony acknowledged his doctor's support and expected that the doctor would manage his illness:

*A great deal from my doctor...who looked after me from the beginning until now, and they are still looking after me, of course, as a patient, which I am, so many years. He has to look after it, that's the truth. (Anthony)*

Michael became accustomed to the absence of support from friends and family. His only support was his doctors, and the aged care home where he resided:

*Only the doctors, nothing else, I don't have relatives, nobody. At the beginning, it was difficult. Afterwards, it became easier. (Michael)*

One participant highlighted the importance of familial support. Bill believed that familial support was more dedicated and helpful than support from friends and relatives:

*The social support will come from your family, because your friend, relative, cousin, will come one day to ask how you are, how you're going. He'll leave. Your family will be near you and they'll look after you, support you, [and] help you as much as you want. (Bill)*

Spiro felt that healthy people were un-empathic towards ill peoples' experiences. He believed that only ill people could understand illness experience:

*Those who are well cannot understand how bad it is for the ill people. There is nobody who knows. However, frequently, they tap you on the back and afterwards they stand up and leave at 5:30 and tell you goodbye. If you suffer and feel pain and are ill, only you know your own pain. Nobody else can take your pain. (Spiro)*

Anthony claimed that others could not help him with his illness, relying instead on his own courage and knowledge. Yet, he often found himself succumbing to his cravings for sugar (consequences):

*The only thing that I have used is that I myself am strong so that I can come out from the situations. Only me, nobody else, because even if someone wanted to help me, he can't help me! To tell me something I don't know? I know it all. It's not one year, it's 33 years! (Anthony)*

In summary, participants' views regarding the role of support for their illness varied. Participants distinguished between the roles of medical support from hospitals, doctors, and medication, and social support, particularly support from family and friends, including conversations and being consoled. One participant (Anthony) viewed external support (professional care) to be unnecessary, while another participant (Peter) viewed it to be a liability because of stigma. Support from friends and relatives was viewed to be un-empathic by one participant (Spiro), and no more helpful than what another participant (Anthony) could do himself, through his own courage and knowledge. Several participants (Anthony, Peter) also expressed a need for independence.



**The importance of social interaction.** With a few exceptions (Peter, Michael), participants highlighted the importance of social interaction regarding their illness experience. Bill valued reciprocal sharing and empathising of illness experiences. He also valued social contact with friends, which helped improve his mood and provide him with encouragement and company:

*A very beautiful thing to have contact with people, to say a joke, to talk about your pain, and for them to understand you, like I want someone else to tell me his pain, I'll understand him. I'll feel it. If I can help him, I will, if I can't, I can't. Sorry. After having gone through these illnesses with my wife together, our friends have always been near us, which gives you a big relief, it gives you a lot of happiness, you forget your pain. A friend, relative, whoever comes, he has a good conversation with you, and that is valued and gives you courage in life. (Bill)*

Spiro claimed that he would “go crazy” when alone with his illness. He appeared to use social activities with his family as a way of avoiding the discomfort of sitting alone with his illness:

*When I'm ill and don't see anyone, I go crazy. I didn't want that to happen to me, and despite this, I'm doing rather well. I enjoy myself. I say lets' go for an outing to Sorrento, and we go. (Spiro)*

On the other hand, following his coronary artery bypass graft surgery, Peter withdrew from any further social interactions because of the perceived stress that he associated with them:

*From the time I did the operation, a weight lifted off my shoulders. I left the conversations. I left the seriousness. (Peter)*

Michael avoided social interactions, which made him feel uncomfortable. The absence of connections with friends, family members, or relatives throughout his life reinforced his familiarity with being alone:

*I don't want to go to a lot of bother. I don't want to go to many visits. I want to always be alone, on my own. It's difficult for me, now that they bring me to a circle with many people around me. I want my solitude and peace, nothing else. I feel uncomfortable. I don't want fuss. I don't want noise. I want to be on my own. Quiet. (Michael)*

In summary, social interactions were viewed to be important for providing encouragement and company, improving mood, and providing an outlet. On the other hand, one participant (Peter) limited social interactions following illness onset to reduce stress, while another participant (Michael) had become accustomed to limited social interactions.

In conclusion, participants' search for meaning varied, as did their process of coming to terms with illness. Participants learnt to face illness and became accustomed to illness. They also resorted to cultural attributions ('luck', 'fate').

Participants also adapted to their chronic illness by accepting their illness. Employing a pragmatic approach enabled Peter to adapt constructively to his illness. On the other hand, Michael's inability to come to terms with his illness was emphasised by a sense of helplessness. Harry's resignation to his illness was mediated by age and a reliance on medical help. Rejection of suicide and a necessity to habituate to treatment requirements also aided the process of illness adaptation for Peter and Bill.

Participants' benefits from illness included positive evaluation of life achievements, comparative evaluation of participants' lives with people perceived to be less fortunate, heightened appreciation of life, and changing life-style to effect better quality of life. Participants also found a purpose in life, which comprised of goals to live and witness child relatives attain developmental milestones, to affirm life, to improve relationships with friends and family, and to live well for the remainder of life. In contrast, Michael experienced a loss of purpose in life following illness.

There was a distinction between the roles of social support, particularly support from family and friends, including conversations and being consoled, and medical support from hospitals, doctors, and medication. Professional care was viewed by Anthony to be unnecessary, and by Peter to be a liability because of stigma, with both participants also expressing a need for independence. Spiro perceived that support from friends and relatives lacked empathy, whilst Anthony believed that only he could help himself through his own courage and knowledge. There were also positive views of social interactions, such as improving mood, providing an outlet, and providing encouragement and company. However, a few participants experienced limited social interaction such as Peter's limited social interactions because of the perceived stress they caused him, and Michael's adaptation to limited social interactions.

## **Chapter 9**

### **Discussion**

This chapter discusses the findings presented in Chapters 7 and 8 and refers to data collected from semi-structured interviews with participants, as well as participants' item responses to the RAND SF-36 questionnaires. The chapter discusses the findings in relation to the research questions stated in Chapter 6 and also refers to the reviewed literature in the first five chapters of this study. The first three research questions explored participants' illness perceptions and coping procedures in relation to the CSM, as well as the relationship between their illness perceptions and their coping procedures. Findings indicated that there was concordance as well as discordance between participants' illness perceptions and their methods of coping. The fourth and fifth research questions explored participants' psychosocial and cultural aspects of their adjustment to chronic illness as well as social influences (social support and social interactions) on their chronic illness experiences. With the exception of one participant (Michael), findings indicated that, in general, participants were able to negotiate their adjustment to chronic illness leading to positive adaptational outcomes. Findings also indicated that there were both positive and negative consequences associated with social influences. The discussion chapter also reviews the strengths and limitations of the present study. The implications of the findings for health care practices and the researcher's experience of the study are also discussed, and recommendations for further research are proposed. The discussion ends with concluding remarks regarding the present study.

#### **Perceived Causes of Chronic Illness**

Patients' causal attributions of chronic illness have been associated with coping and psychological adjustment (Roesch & Weiner, 2001). According to Hirani

and Newman (2005), causal attributions of illness appear to guide behaviour. For example, coronary heart disease patients who attribute the cause of their illness to genetic or hereditary factors (external causes) may adopt a fatalistic approach to their illness and maintain behaviours detrimental to their health (diet, smoking).

Participants in the present study predominantly attributed the cause of their chronic illness to external factors (Weiner, 1986), such as biological and hereditary factors, and stressful life events. This may have contributed to a belief that their illness was beyond their control, potentially interfering with their willingness to assume responsibility for managing their chronic illness. Consistent with mind-body dualism (Samson, 1999b) and disease related to physical bodily changes (Crossley et al., 2001), Harry believed that his body was the cause and location of his multiple illnesses (glaucoma, gout, prostate cancer, chronic stomach condition [intestinal inflammation]). This implies that disease was imposed by circumstances or conditions outside of the patient's control or understanding (DuCette & Keane, 1984) requiring repair by the doctor or surgeon following malfunction (Crossley et al., 2001), which was consistent with Harry's medical help-seeking behaviour. Anthony did not cite any modifiable risk factors (internal causal attributions) for the cause of his illness (diabetes) but instead related it to genetic inheritance (external causal attribution), which may have potentially impacted on his ability to assume responsibility for the management of his illness (blood glucose monitoring, diet). Peter's belief that his illness (coronary artery disease) was primarily caused by a genetic susceptibility to stress may have contributed to contradictory health behaviours. Whilst he engaged in positive health behaviour (exercise [walking]) to reduce his stress, he also experienced difficulty in other areas (weight management). This was possibly related to a perception that stress was more influential than other risk factors (diet) and that it

needed to be avoided for fear of experiencing another heart condition (Clark, 2003). Stressful life events, mediated through behavioural responses (smoking) to cope with stress, have been highlighted as a risk factor for disease (Cohen et al., 2007), and have impacted on quality of life and mental health (Lu et al., 2012). In the present study, it appears that Michael's belief that his stressful life event (loss of business and house), lifestyle behaviour (smoking), and emotional response (worry) caused his illness (chronic obstructive pulmonary disease [COPD]) was related to negative outcomes (poor mental health, reduced quality of life).

### **Perceived Consequences of Chronic Illness**

Consequences of chronic illness perceived by participants ranged in severity and were arranged into themes of physical, psychological, and social consequences. The physical consequences of chronic illness were associated with the reality of living with daily routines, and the impact of chronic illness on physical activity and stamina. Two participants' (Bill, Anthony) perceived consequences regarding daily routines appeared to have both positive and negative impacts on the management of their chronic illness. Bill's awareness of serious consequences (need for daily computerised home haemodialysis for survival [Bayhakki and Hatthakit, 2012]) was concordant with his motivation and commitment to manage his illness (adherence to daily haemodialysis). On the other hand, Anthony's emotional consequences (concern with avoiding hypoglycaemia [low blood glucose] [Ahola & Groop, 2013]) may have potentially contributed to avoidant or overcompensating behaviour (overriding regulated diet to increase blood glucose levels and avoid hypoglycaemia). Furthermore, his perception of low controllability (ineffective attempts at regulating blood glucose levels [Peel et al., 2007]) may have contributed to his reduced motivation and commitment to manage his illness (frequent self-monitoring, diet).

Symptoms attributed to ageing (age-illness rule), including symptoms with a gradual onset, have led to delays in seeking medical help (Leventhal & Crouch, 1997; Prohaska et al., 1987), potentially increasing morbidity and mortality (Leventhal & Crouch, 1997). Two participants' (Bill, Harry) perceptions regarding illness consequences (reduced physical strength), which appeared to be influenced by their views concerning age and other illness co-morbidities, may have potentially contributed to avoidant behaviour (delay in seeking medical help), that also potentially exposed them to further health risks. Peter's perceived physical consequence (inability to engage in physical exertion [lifting weight]) was concordant with his avoidant behaviour (avoiding physical exertion). Peter did not indicate any reason for his avoidant behaviour, which persisted long after his coronary artery bypass graft (CABG) surgery and subsequent rehabilitation. However, it may be that he was concerned about strenuous physical activity exacerbating his stress level, perceived to be the cause of his illness (Clark, 2003; Hirani & Newman, 2005), leading to a heart condition (Clark, 2003; Martin et al., 2003), which was also moderated by his understanding that others had died from similar situations. Thus, he may have been inclined to conserve his energy (conservation heuristic) (Martin et al., 2003). Alternatively, it may be that he avoided physical exertion in order to alter the impact of his illness (coronary artery disease [CAD]) and subsequent surgery on his life (Janoff-Bulman & Frantz, 1997). The type of information (or lack of) given to patients by medical professionals in the early stages of illness may also contribute to patients' concerns with physical exertion (Parker & Adams, 2008).

The psychological consequences of chronic illness in the present study included the difficulty of resisting temptations and managing the requirements of illness, and emotional reactions to illness. Two participants' (Anthony, Bill) perceived

consequences associated with temptations appeared to have contrasting influences on their adherence to their treatment regimen to manage their chronic illness. According to Uchenna et al. (2010), patients with diabetes who have not been tempted were found to adhere to their dietary management. However, in the present study Anthony's perceived psychological consequences (claimed "weakness" for sugary food, resigned inability to moderate dietary intake) was concordant with his problematic dietary behaviour (inability to moderate food intake) that also impacted negatively on the management of his illness. This may have been related to an expectation that he was incapable of resisting his temptation (Martijn et al., 2006). Alternatively, Anthony's temptation may have reflected a causal attribution which was personal to him (his "weakness") and unlikely to change, even if it was potentially controllable, because he viewed it as part of his own makeup or habitual behaviour (Wearden et al., 2006). Conversely, Bill's awareness of serious consequences in exceeding his daily diet and fluid intake limit was related to management of his illness through self-control (resisting temptations) and adherence to the treatment regimen (self-monitoring of dietary and fluid intake limits). This was consistent with Chilcot et al. (2010) where patients with end stage kidney disease who perceived fewer consequences displayed non-adherence to fluid restrictions. Anthony's perception of negative consequences (daily visual reminders of illness [symptoms, treatment requirements]) also potentially contributed to his problematic illness management (reduced treatment adherence [self-monitoring]). This may have resulted from his reduced self-efficacy and motivation, and an expectation of negative outcomes (Martijn et al., 2006). This also appears to be consistent with Aljasem et al. (2001) who found that confidence to perform diabetes treatment-related behaviours



(diet, self-monitoring, testing), or treatment self-efficacy, was related to improved performance in these self-care behaviours.

Emotional representations of illness, the second path of the CSM (Leventhal et al., 2003), have also been associated with coping procedures and illness outcomes (Hagger & Orbell, 2003; Moss-Morris et al., 2002). In the present study, Bill's psychological consequences associated with emotional responses (anxiety, sadness) were related to his use of a cognitive coping strategy (coping self-talk) to regulate his emotions. Anthony's emotional response (anxiety), which he believed needed to be regulated in order to prevent further exacerbation of his illness, was related to his use of cognitive (avoiding negative thoughts about illness) and behavioural (relaxation) coping strategies to regulate his anxiety. However, his focus on his anxiety may have potentially interfered with his ability to attend to other self-control aspects of his illness (adherence to treatment regimen) (Tice & Bratslavsky, 2000).

In social settings, there was non-disclosure of illness and comparisons of illness as well as dissonance between valued Greek influences (Greek hospitality) and self-management of illness,. Hospitality or *filoxenia* in Greek, which is highly valued in the Greek community (Greek Care, 2013g), has been shown to negatively influence dietary adherence for Maltese-Australians with diabetes (Barbara & Krass, 2013). Dietary non-adherence following non-disclosure of illness (diabetes) in social settings has also been reported (Uchenna et al., 2010; Krepia et al., 2011). In the present study, there were social consequences related to two participants' (Anthony, Bill) perceptions of Greek hospitality that appeared to influence their dietary adherence and quality of life. For instance, Anthony's perceived social consequence (concern with disclosing dietary restrictions [sugary foods]), particularly in the presence of unfamiliar people, contributed to his difficulty with self-control (dietary non-

adherence). Bill's avoidant behaviour (avoidance of social encounters), which also impacted on his quality of life, was also related to his perceived social consequence (concern with creating anxiety in others by declining their hospitality because of restrictions [diet, fluid]) (Kaba et al., 2007).

In the present study, the social consequences regarding participants' perceptions of themselves following social comparisons of chronic illness were related to positive and negative outcomes. According to Leventhal et al. (1997), social comparisons may serve different functions depending on the situation. Consistent with Wills (1981), Anthony's downward social comparison in the present study was related to positive outcomes (improved mood, self-esteem). It has also been argued that self-enhancement may result from upward or downward social comparisons (Buunk et al., 1990; Collins, 1996; Wills, 1981). However, in the present study, two participants' (Spiro, Peter) upward social comparisons were related to negative outcomes (negative perceptions of health and quality of life, psychological distress). This may have been related to participants' interpretation of their social comparison with others rather than the direction of comparison (Collins, 1996). Participants' subjective accounts of social comparisons of illness were also generally supported by their objective measures (RAND SF-36). However, Peter's social comparisons appeared to be contradictory. For instance, his comparison with his best man contributed to a negative view of his own health, which contrasted with his positive view of his own health ("extremely healthy", 'wish' for others to be as healthy as himself) following comparisons with others (author of the present study, general others). It may be that Peter viewed himself to be healthy when his condition was stable or when he perceived himself to be more fortunate than others (Wills, 1981).

There were also social consequences concerning participants' perceptions of stigmatisation and discrediting following disclosure of chronic illness, particularly illness that is not visible to others (Goffman, 1986; Joachim & Acorn, 2003), which were related to cognitive coping strategies (participants' decision whether or not to disclose their illness). According to Joachim and Acorn (2000), individuals with illness have held beliefs that they would not "pass for normal" (p. 245) following illness disclosure. In the present study, two participants' (Spiro, Anthony) fear of being stigmatised and discredited (Goffman, 1986) was concordant with their decision not to disclose their chronic illness. Avoiding unwanted attention (social consequence) has also been associated with a reluctance to disclose illness (cognitive coping strategy) (Joachim & Acorn, 2003). This was consistent with Spiro and Anthony's beliefs in the present study that revealing chronic illness would attract unwanted sympathy, which was also concordant with their decision not to disclose their illness. According to Charmaz (1991), chronically ill individuals could display preferred identities by choosing not to disclose illness. In the present study, Spiro's social behaviour (displaying a preferred identity signifying health ["I want them to see me strong!"]) was related to his perceptions of psychological consequences (beliefs about self-worth) and social consequences (concerns about feelings of sorrow from others). Individuals with chronic illness have also chosen to hide concerns about illness from their spouses because of fears of upsetting them (protective buffering) (Suls et al., 1997). In this study, Anthony's attempt to conceal his illness from family members, by displaying a positive affect ("display happy"), was concordant with his perception that his illness would distress his family members. His reluctance to disclose his illness to others was also concordant with his concern about experiencing rejection and receiving negative reactions (annoyance) (Charmaz, 1991).

## **Perceptions of Chronic Illness Controllability**

Participants' views concerning their ability to control their illness (controllability) were arranged into themes of treatment control and personal control. Participants' beliefs regarding controllability of their illness through treatment (treatment control) were concordant with their use of medical services (reliance on medical professionals and medication, as well as medical equipment). Moreover, participants' beliefs in the importance of medical professionals for the control of their illness were concordant with their medical help-seeking behaviour and, in some cases (Harry, Anthony), appeared to be related to their reluctance to assume responsibility for their illness. Harry's belief that he was actively involved in controlling his illness by seeking medical help (medical professionals, medication) contrasted with the reality of relying on his medication and handing over responsibility for the management of his illness to his doctors because of his age. It may be that, in reality and in contrast to his belief, Harry viewed his health problems and bodily deterioration as an inevitable process of ageing that was best managed by his doctors (Jolanki, 2009), which also conserved his resources and resolved symptom uncertainty (Leventhal et al., 1995). Anthony believed that he could control his illness by relying on his doctors who had the knowledge and could provide him with the appropriate advice related to treatment for his condition (Koch et al., 2004). Yet, in reality, his behaviour (engaging in treatment to please his doctors) may have reflected a passive role (Almyroudi et al., 2011), which may have also hampered his commitment towards the management of his illness. Spiro also believed in the importance of medical professionals for the control of his illness, which was concordant with his medical help-seeking behaviour, and compliance with his doctors' instructions. Bill's perception regarding the importance of medical

equipment (computerised home haemodialysis) for the control and survival of his illness was concordant with his commitment and adherence to his daily haemodialysis. His positive appraisal of his treatment (haemodialysis) also appeared to strengthen his belief in his ability to control his illness over time (Tasmoc et al., 2013).

Participants' beliefs regarding personal control of chronic illness in the present study ranged from changes in lifestyle behaviour, such as engaging in activities to reduce modifiable risk factors (diet, exercise), to self-control measures aimed at regulating physical and emotional aspects of illness. For two participants, their beliefs regarding personal control of their chronic illness were discordant with the reality of managing their illness, in some instances. Peter's belief that he could control his illness (coronary artery disease) through health behaviour change (smoking cessation, exercising [walking]) resulted in positive outcomes. However, his belief in eating a healthy and balanced diet to control his illness did not translate to health behaviour change in other areas (weight management). This may have been related to Peter's reduced self-efficacy following repeated unsuccessful attempts to manage his weight, or to the absence of a lifestyle risk factor (diet) from his beliefs about the causes of his illness (smoking, stress). Anthony's belief that he could control his illness (diabetes) by adhering to the treatment requirements (self-monitoring, dietary and fluid intake) was discordant with the reality of adhering to his treatment regimen (Ingadottir & Halldorsdottir, 2008), leading to self-regulatory problems (Sheeran et al., 2006). Negative emotions can also interfere with self-control efforts when individuals focus on regulating their emotions to avoid emotional distress (Tice & Bratslavsky, 2000). In the present study, Anthony's belief in the importance of controlling his illness by managing his anxiety (concern that anxiety

will exacerbate his illness) was concordant with his focus on regulating his anxiety (avoiding negative thoughts about illness, relaxation). However, his focus on emotion regulation may have also interfered with the management of his illness by diverting his attention away from his efforts at self-control (adherence to the treatment regime) (Tice & Bratslavsky, 2000).

### **Coping Procedures for Chronic Illness**

Coping procedures are the actions, cognitive or behavioural, undertaken by individuals in their attempts to regulate their illness (Leventhal et al., 1998). Illness representations have been associated with coping procedures for chronic illness (Hagger & Orbell, 2003). Coping procedures have also been shown to mediate the relationship between illness representations and outcome (Rutter & Rutter, 2002). In the present study, participants' medical help-seeking behaviour and compliance with their doctors' instructions were concordant with their beliefs in the importance of medical professionals for the control of their illness (Koch et al., 2004; Thorne, 1993), but for different reasons. Spiro's reliance on his doctors, and his unconditional compliance with their instructions, was consistent with his belief in the importance of medical professionals for the management of his illness (diabetes). Anthony's reliance on his doctors was also concordant with his belief in the importance of doctors to control his illness (diabetes). However, his claim that he engaged in medical treatment to please his medical team ("To make them happy") appeared to reflect a passive compliance with medical professionals. Harry's willingness to surrender responsibility for the management of his illness to his doctors and his reliance on medication, after citing his advanced age (Jolanki, 2009), was discordant with his belief that he was actively involved in managing his illness by seeking medical help. Participants' passive compliance with their doctors' instructions (Wrede-Sach et al.,

2013) was possibly related to contextual influences within the Greek culture, such as medical decision-making based on paternalism in the doctor-patient relationship (Almyroudi et al., 2011). Language barriers between doctor and patient may have also played a part in their passive compliance (Tang & Anderson, 1999).

Two participants' (Bill, Michael) coping methods of relying on life-sustaining medical equipment for survival and illness self-management were related to their illness representations. Bill's commitment and active engagement in managing his treatment (computerised home haemodialysis), which also appeared to increase his self-efficacy, was concordant with his awareness of serious consequences (mortality through non-adherence to haemodialysis), as well as his belief in no alternative options to control his illness (end-stage kidney disease [ESKD]). Michael's awareness of the serious consequences of not adhering to the use of oxygen therapy (OT) for his illness (chronic obstructive pulmonary disease [COPD]) was also concordant with his engagement in its use.

Engaging in health behaviour change was a coping strategy used by two participants (Spiro, Peter), which was also related to psychological consequences regarding emotional responses (concerns about health). Spiro's emotional response (concern about further illness deterioration and complications) was concordant with his coping procedure (health behaviour change [exercise]), which also increased his self-efficacy ("I can see and walk well and that's okay"). Peter's health behaviour change (exercise combined with distraction techniques [visual imagery]) may have been related to his causal belief about his illness (stress was more influential than other risk factors [diet]) and an emotional response (concern that stress needed to be avoided for fear of experiencing a heart condition [Clark, 2003]).

Adopting self-control was another coping strategy used by participants to manage their chronic illness, which in some cases (Anthony, Peter) was discordant with their beliefs regarding control of their illness. Illness representations have been associated with self-control (adherence to fluid intake restrictions) by patients with end-stage kidney disease (ESKD) on haemodialysis (Chilcot et al., 2010; O'Connor et al., 2008). For example, perceived consequences predicted fluid adherence with lower perceived consequences increasing the likelihood of non-adherence (Chilcot et al., 2010). In the present study, Bill's awareness of serious consequences (complications associated with exceeding daily fluid intake) was concordant with his adherence to his treatment regimen (dietary and fluid intake restrictions). On the other hand, Anthony's dietary self-control continued to be problematic, despite a successful five year period of controlling his illness (diabetes). His perceived psychological consequences regarding his dietary adherence (propensity for sugary food, resigned acceptance to excess dietary consumption) were concordant with his inability to maintain self-control (inability to moderate dietary intake) for the management of his illness. Perhaps his difficulty with maintaining dietary self-control was related, in part, to attributing his temptation for sugary foods to a personally relevant factor ("I have a weakness") (Wearden et al., 2006) that was also perpetuated in social contexts involving Greek hospitality. In accordance with Baumeister and Heatherton (1996), Anthony's difficulty in regulating the self may have also been related to his inability to "transcend the effects of the immediate stimuli" (p. 4) because of situational and dispositional factors. Conversely, Anthony's belief in his ability to control his illness (personal control) by adhering to his treatment regimen, and his appraisal of his illness self-management (managing his illness "to a reasonable extent") were discordant with the reality of not adhering to the requirements to manage his illness



(reduced self-monitoring, acquiescing to sugary foods, exceeding dietary intake). It may be that Anthony's negative expectancy in his ability to control his illness (Martijn et al., 2006), such as regulating his diet ("I always make the mistake and eat more than I should...I can't do anything else") and regulating his blood sugar levels, contributed to his low motivation ("I can't be bothered because I know the feeling") that also negatively influenced the management of his illness (reduced frequency of daily self-monitoring, acquiescing to temptations) (De Ridder & Kuijer, 2006). Peter's belief in the importance of a moderate and healthy diet to control his illness (coronary artery disease [CAD]) was discordant with his unsuccessful attempts at dietary self-control (excess weight), a risk factor for CAD, which may have been related to reduced self-efficacy following repeated unsuccessful attempts at weight management. Alternatively, his beliefs about the cause of his illness, which included some known risk factors (smoking) but not others (diet), may have contributed to this self-control discrepancy.

Emotional representations have been associated with coping strategies for regulating emotion, which also had the potential to influence self-care behaviour (O'Connor et al., 2008). In general, participants' coping strategies for emotion regulation were related to their emotional responses. Michael's coping strategy (distraction [listening to music]) was related to his experience of negative emotional responses (depression, anxiety) from recollections of previous stressful life events (loss of business and house). However, his avoidant coping strategy did not help him to come to terms with the losses relating to these events that continued to intrude on his life. Anthony's emphasis on his coping strategy (relaxation, spending time on his own) for emotion regulation was concordant with his emotional response (elevated concern about anxiety exacerbating his illness). However, his emphasis on regulating

his anxiety potentially jeopardised his self-control efforts in other aspects of his illness (adherence to treatment regimen) (Tice & Bratslavsky, 2000). Harry's coping strategy (altered self-identity displaying composure and courage [public self]) was related to his belief that exhibiting negative emotional responses (anxiety, depression [private self]) were detrimental to his health and were best avoided (Charmaz, 1995b). Bill's cognitive coping strategy (positive self-talk) for emotion regulation was also concordant with his emotional responses (anxiety, sadness).

### **Psychosocial Adjustment to Chronic Illness**

As part of their adjustment to chronic illness, participants' search for meaning and their process of coming to terms with illness in the present study was generally related to attempts to alter the meaning of their chronic illness or their global meaning (values, beliefs, goals) (Park & Folkman, 1997), with mixed results. It appears that Bill's search for meaning following his illness (end-stage kidney disease [ESKD]), coinciding with a perceived change in his masculine, familial, and spousal roles (Charmaz, 1995b), was related to a change in his global values, particularly taken-for-granted events such as appreciating each day ("Take one day at a time") (Skaggs & Barron, 2006), which also aided his adaptation to his illness. On the other hand, Anthony's attempt to change the meaning of his illness (diabetes), by altering his self-identity that relied on inner strength to manage his illness ("I have it. I have to fight it") (Charmaz, 1995b), was discordant with the reality of managing his illness. Despite his claimed inner strength, it may be that by viewing his illness to be predetermined ("That's written in the books") (Avgoulas & Fanany, 2012), which was most likely related to an external causal attribution that was beyond his control, Anthony had absolved himself of his responsibility for managing his illness. As part of his search for meaning, Spiro's attempt to attribute his illness (diabetes) to his own

bad *τύχη* (luck), rather than other external elements (people, God), possibly masked an altered self-identity with illness, which had also become evident in his upward social comparison with other healthy individuals. His refocus on global meaning (i.e. valuing his accomplishments) (Avgoulas & Fanany, 2012) may have also reflected an attempt to compensate for his altered self-identity with illness that also enabled him to derive meaning from his illness. Life event stress has also been shown to adversely affect the mental health and quality of life for individuals with chronic obstructive pulmonary disease (COPD) (Lu et al., 2012). In contrast to other participants, it may be that Michael's inability to find meaning and come to terms with his illness (COPD) was related to his inability to re-appraise and integrate the meaning of the stressful life event (loss of house and business) with his beliefs, values, and goals (global meaning) or to alter his global meaning (Park & Folkman, 1997), contributing to negative outcomes (despair, helplessness, low self-worth) (Park & Folkman, 1997; Skaggs & Barron, 2006).

Participants' adaptation to illness included an acceptance of illness, adopting a pragmatic approach to illness, and resigning to illness which was mediated by age and a reliance on medical help. Accepting the reality of stressful situations as well as growing from adversity, by making the best of negative situations, has been related to optimism (Scheier & Carver, 1993). Despite a possible altered self-identity following his search for meaning, Spiro's resignation to his illness ("inevitable") appeared to help him come to terms with his illness and accept the reality of his condition, which also enabled him to adopt a positive outlook on life ("My aim is to be happy"). Moreover, Spiro's adaptation to his illness appeared to reflect a shift from focussing on his illness (illness in the foreground) to focussing on living well (wellness in the foreground) (Paterson, 2001). Adopting a pragmatic approach to chronic illness has

been associated with illness adaptation for elderly individuals experiencing stroke (Pound et al., 1998). Despite his concern about physical exertion (lifting weight), it appears that Peter's pragmatic approach following his coronary artery bypass graft (CABG) surgery ("Whatever you can, you'll do. You'll manage") enabled him to adapt to his illness. Despite Harry's resignation to his illness, which was mediated by age and a reliance on medical help (medication, doctors) (Jolanki, 2009), his altered self-identity with illness reflecting self-assurance and resilience ("For the age I'm at, I'm well") (Charmaz, 1995b) helped him to live with his illness. Peter and Bill's reaffirmation of their resolve and commitment to accept and adapt to the reality of their illness, including a rejection of suicide, was also possibly related to their ability to come to terms with their initial emotional reactions (fear, uncertainty) relating to their early illness experiences (coronary artery bypass graft [CABG] surgery [Peter], commencement of haemodialysis [Bill]). An internal health locus of control has been associated with health-related quality of life and mental health for patients with end-stage kidney disease (ESKD) (Paraskevi, 2011). In the present study, Bill's positive adaptation to his illness (ESKD) and treatment regimen (fluid and diet adherence, computerised home haemodialysis) appeared to be related to an understanding of his illness (illness coherence) and a positive appraisal of his ability to control his illness though his daily haemodialysis treatment (internal locus of control), resulting in increased self-efficacy and acceptance of his haemodialysis.

The search for meaning for individuals experiencing adversity (Park & Folkman, 1997) has also resulted in perceived benefits (Affleck & Tennen, 1996), including patients with chronic illness (Danoff-Burg & Revenson, 2005; Kutner et al., 2000). In the present study, participants' perceived benefits from their chronic illness included a focus on aspects of life previously taken for granted. Despite his

problematic illness management, Anthony's belief in benefiting from a renewed appreciation of life, as well as maintaining a relatively good quality of life that included a valued cultural quality (Greek hospitality) may have been related to a re-evaluation of his quality of life following illness. For instance, it may be that he modified his standards and values as well as his conceptualization (redefinition) of quality of life (response shift) (Sprangers & Schwartz, 1999) following downward social comparisons with his compatriots in Greece (Wills, 1981). According to Kutner et al. (2000), increased life satisfaction was a benefit experienced by older patients with chronic illness over time as they adapted to treatment and the constraints of their illness. This was consistent with two participants in the present study (Spiro, Bill) who perceived that they benefited from a positive evaluation (satisfaction) of life achievements.

Finding a purpose by striving for goals is another aspect associated with the search for meaning following illness, which has also been related to general life adjustment (Park & Folkman, 1997). Carver and Scheier (1998) emphasised that goal engagement is "a necessity of life" (p. 346) and that "without goal engagement, life ceases" (p.346). With one exception (Michael), participants in the present study engaged in goals that were important to them and provided them with a sense of purpose and meaning in life with illness. Despite Anthony's problematic illness management that potentially limited his long-term survival, he gained a sense of fulfilment and purpose in life from his goal of affirming life in order to live long enough to witness child relatives attain developmental milestones. It appears that Spiro's awareness of an existential reality relating to a limited lifespan with illness influenced him to focus on attaining his goal of improving his interpersonal relationships with friends and family, which also took precedence over other aspects

of his life that had become less significant with illness. After overcoming existential concerns about his survival following his coronary artery bypass graft (CABG) surgery, Peter' newfound purpose in life was a commitment to himself to improve his quality of his life (living well for the remainder of his life). In stark contrast to other participants, Michael's loss of purpose in life following his life event stress (loss of house and business) appeared to reflect a resignation to his illness and a devalued sense of self ("I feel like a finished person") (Charmaz, 1995a), as well as a profound loss of hope in experiencing any positive things in life, including losing the will to live ("There is no life") (Carver & Scheier, 1998).

### **The Perception of Support**

Two participants' (Harry, Spiro) perceptions of support distinguished between medical support and social support for their chronic illness. For instance, Harry and Spiro acknowledged receiving emotional support from family and friends, which they also perceived as being different from medical support from the medical establishment. Their perception of medical support was related to the biomedical view that illness was a medical problem that could only be helped through assistance from the medical establishment (Crossley et al., 2001), whilst their perception of social support highlighted the role of supportive network ties on mental health and wellbeing (Heany & Israel, 2008). Anthony's expectation for medical care from his doctor may have been related to passive behaviour that reflected a preference for his doctor to assume responsibility for his illness (Koch et al., 2004). It also appears that emotional support (interpersonal interactions), which was valued above instrumental support (financial help), facilitated positive mental health and psychological wellbeing (Rook, 1990) for two participants (Anthony, Spiro). Conversely, some of the participants (Anthony, Peter) viewed external support to be unnecessary. For instance, Anthony's

decline of external support (professional care), because of his preference for independence, was discordant with support received from family members (spouse, children), which implies that he was dependent on support. It may be that his subjective perception of independence was related to his way of evaluating the assistance received from familial members (Gignac & Cott, 1998). Eliciting patients' evaluations of independence may help facilitate appropriate support to match patients' perceptions of independence. On the other hand, Peter's refusal of external support was related to his need for independence, as well as his concern about being stigmatised and discredited as a patient who is "different" from others (Joachim & Acorn, 2000). It may be that he perceived external support to threaten his self-identity as a healthy individual (Charmaz, 1995b). Furthermore, Peter's refusal of external support placed him at risk of forgoing external support when it was really needed. In general, the presence of support from friends and family was valued by most of the participants in the present study. However, there were some exceptions. According to Berkman and Glass (2000), an individual receiving empathy, love, and caring is said to be emotionally supported. Yet, one participant (Spiro) viewed support from friends to be deprived of empathy, and felt that others did not understand his difficulties. This may have left Spiro feeling alone with his illness, and may have also highlighted dissatisfaction with the quality of support received. According to Bell et al. (1982), social support provides "an ameliorative function against the deleterious effects of life events" (p. 336). However, the absence of social support in Michael's case may not have protected, or buffered, him from adversity that followed from his stressful life event (loss of house and business) (Heany & Israel, 2008).

## **The Perceived Value of Social Interaction**

In general, participants in the present study perceived their social interactions to be beneficial, as providing encouragement, company, and an affective outlet, improving mood, and helping them to relax. According to Rook (1990), companionship may help divert attention from self-scrutiny, such as focussing on oneself and one's shortcomings, which can potentially increase negative affect. In the present study, Spiro's reliance on familial social interactions (activities) to distract him from ruminating about his illness also improved his mental health and psychological wellbeing (Rook, 1990). However, not all social interactions are positive. Negative social interactions have been shown to have a negative impact on wellbeing for the elderly (Gallant et al., 2007). This did not appear to be the case for Peter, who improved his wellbeing by limiting his social interactions following his coronary artery bypass graft (CABG) surgery. This may have been related to his CABG surgery creating an opportunity for him to reflect on and re-prioritise his social interactions, which he viewed to be stressful prior to his surgery. Older individuals may also express a low need for companionship, or develop a resigned acceptance to limited companionship, or feel uncomfortable when forced into social encounters that cannot be declined or when receiving unwanted visits (Rook, 1990). In contrast to most of the other participants in the present study, Michael's adaptation to minimal social interaction, which developed into a preference for his own solitude, meant that he had no social outlet to divert his attention from himself and his shortcomings (life event stress, chronic obstructive pulmonary disease), potentially exacerbating his negative affect (depressed mood) (Rook, 1990).



## **Strengths and Limitations of the Study**

The steps taken in the present study to ensure forms of equivalence, as well as the use of multiple sources of data, helped to enhance the trustworthiness of the interpretations. For instance, one of the methodological strengths of the present study was pilot testing the translated semi-structured interview questions prior to conducting interviews with participants, which also helps to enhance the credibility of the findings particularly for cross-language studies (Squires, 2008). The use of triangulation, which helps to strengthen the validity of claims to knowledge (Marshall & Rossman, 2011), was another strength of this study which used semi-structured interviews as the primary data collection method and supported with the researcher's field notes and information from demographic data and the RAND SF-36 questionnaires. Another strength of the present study was the incorporation of the views of non-English speaking individuals, given the predominance of the English language in science and literature. A further strength was the considerable work that went into the translation of the material used during participant interviewing, including the introductory information, consent forms, interview schedule, and forward- and backward-translations of the RAND SF-36 questionnaire.

A limitation of the present study was the occasional intrusion by a few of the participants' spouses who came within close proximity of the interviewing area, with one spouse in one case and a participant's friend in another case briefly interrupting the interview. This may have potentially influenced some participants' responses, as well as confidentiality. The presence of the interviewer may have also potentially contributed to occasional participant responses that were perhaps aimed at pleasing the interviewer. For example, one participant responded that he was as healthy as the interviewer. Nevertheless, the participants indicated that they felt safe and

comfortable with being interviewed in their own environment, despite being informed about the possibility of intrusions and interruptions. Moreover, whilst the proximity of some of the participants' friends and family members while the interview was being conducted was not preferred by the researcher, the participants were not uneasy about this being the case. The researcher also ensured that he included only the participants' information in the transcripts. Furthermore, the researcher found it extremely difficult to recruit and, as a result, he decided to include the participants in the study. Another limitation of the present study was a small sample size comprising of only seven participants, although this is not usually a critical issue in qualitative research.

Furthermore, the presence of at least one chronic physical illness as the inclusion criteria as well as recruiting in a group setting (i.e. the Greek community clubs) may have potentially contributed to participants' general reticence to disclose the presence of chronic illness during recruitment. Despite the tendency to limit the number of participants, the researcher's difficulty of not knowing whether participants had a chronic illness coming to light at a later stage supported the rationale for maintaining the inclusion criteria of at least one chronic physical illness. It may also be argued that recruiting in a group setting constitutes a form of 'personal identity threat' that had the potential to create perceived dehumanisation, objectification, disempowerment, and devaluation that contributed to participants' reticence to disclose any illness (Coyle, 1999). According to Coyle (1999), 'personal identity threat' indicates identity that "had been undermined in some way by the untoward experience" (p. 107).

However, after addressing the male individuals as a whole in each club setting, the researcher also attempted to attend and talk to Greek-speaking males individually at the tables. This was done in order to create a more personable experience, with the aim of potentially helping to counteract any adverse threat to individuals' identity in

revealing their interest amongst fellow male members when addressing the group as a whole.

### **Comparison of Findings With Other CSM-Based Populations**

Performing comparisons between participants' findings in the present study and studies with other CSM-based populations was complicated by the presence of heterogeneous chronic conditions amongst the participants. Nonetheless, there appears to be concordance between numerous comparisons of participants' illness representations in the present study for their specific illnesses and findings of studies with other CSM-based populations. For instance, findings on perceived psychological consequences relating to Anthony's ineffective attempts at regulating his blood glucose levels for his illness (diabetes) appeared to be consistent with the findings in Peel et al.'s, (2007) study with Scottish participants. In addition, Bill's awareness of serious psychological consequences in exceeding his dietary and fluid restrictions for his illness (end-stage kidney disease) that also influenced his coping procedures (resisting temptations, adhering to dietary and fluid intake) was concordant with the findings in Chilcot et al.'s (2010) study comprising predominantly English participants. Bill's strengthened belief in his ability to control his illness over time following his positive appraisal of his treatment (haemodialysis) was also consistent with Tasmoc et al.'s (2013) findings with Romanian participants. Finally, there was concordance between Bill's positive adaptation to his illness and treatment regimen (fluid and diet adherence, computerised home haemodialysis) based on illness coherence and an internal locus of control and findings related to Greek patients in Greece in a study by Paraskevi (2011).

## **Implications for Practice**

The present study has also developed conceptual insights that may be useful for understanding the chronic illness experiences of different groups. For instance, participants' beliefs regarding the cause of their chronic illness have potential implications for the management of their chronic illness. External causal attributions of chronic illness can contribute to beliefs that illness is beyond individuals' control which have the potential to reduce persistent active engagement in the management of chronic illness, such as adherence to the treatment regimen, and negatively influence their psychological adjustment (Roesch & Weiner, 2001). This has relevance for health care services which have traditionally viewed individuals to be responsible for the cause of their chronic illness, by permitting modifiable risk factors (internal causal attributions) to develop, and targeting individuals to alter their behaviours in order to reduce these modifiable risk factors. Individuals' beliefs based on external causal attributions have potential implications for the way they manage and adjust to their chronic illness. Thus, health care services may better serve chronically ill individuals by including an understanding of their causal beliefs in the provision of health care to facilitate improved management and adjustment relating to their chronic illness.

Individuals' views regarding the consequences of their chronic illness, including perceptions of their seriousness, may influence their commitment and motivation towards their chronic illness management as well as potentially affect their adjustment to their chronic illness, such as their mental health and quality of life. Moreover, the influence of contextual (social, cultural) factors on individuals' perceptions of the consequences of their chronic illness may also guide their chronic illness management, such as their ability to maintain self-control in the presence of others. A consideration of the individuals' views regarding the consequences of their

illness, as well as contextual (socio-cultural) influences, by health care services may help to facilitate an understanding of the impact on the commitment and motivation displayed by individuals towards their chronic illness management, and psychosocial adjustment, in order to inform and improve treatment planning.

Participants' beliefs in the importance of medical professionals for the control of their chronic illness also have important implications for their chronic illness management by potentially creating an expectation that medical professionals should assume responsibility for the management of chronic illness (Koch et al., 2004). This is perhaps related to participants investing medical professionals with expertise and knowledge, which may be partly influenced by their culture (Karnilowicz, 2010; Tang & Anderson, 1999). Thus, an understanding of patients' beliefs regarding ownership and responsibility for their chronic illness, and the socio-cultural context in which this occurs, may help to establish collaborative health care practices between health care providers and their patients (patient-centred care), which could also potentially help patients to assume more responsibility for managing their chronic illness.

The present study has also shown that participants' beliefs regarding personal control of their chronic illness can also differ from the reality of managing their illness and can lead to self-regulation failure (Baumeister & Heatherton, 1996). This may be related to differences in their expectations, motivations, self-efficacy, as well as socio-cultural influences. One participant's belief in the importance of regulating emotions above other self-control aspects of chronic illness implies that emotions were perceived as more detrimental to health and therefore required more attention, perhaps at the expense of other aspects of chronic illness management, such as adherence to treatment regimen. Thus, an understanding of patients' beliefs regarding

the personal controllability of their chronic illness, including an understanding of the focus on emotion regulation, potentially above other self-control tasks, is important because it may assist health care professionals to understand the reasons behind the discordance between participants' beliefs and the reality of managing their chronic illness in order to facilitate change in this area.

An understanding of participants' psychosocial adjustment to their chronic illness, including contextual (social and cultural) factors that can potentially influence the adjustment process, is useful because it has implications for their mental health and quality of life. Successfully negotiating the psychosocial adjustment processes for chronic illness in the conceptual model by Sharpe and Curran (2006) has shown in the present study that it can lead to benefits, such as finding a purpose in life, generating new goals or re-prioritising values, and maintaining a reasonable quality of life. However, the present study also highlighted, for one participant, an inability to navigate the psychosocial adjustment processes of chronic illness resulting in negative adjustment outcomes relating to a diminished quality of life and poor mental health. The findings for this participant imply that other factors, in this case a stressful life event (loss of house and business), perceived to be a primary cause of his chronic illness (chronic obstructive pulmonary disease [COPD]), may have contributed to his difficulty in adjusting to his chronic illness. Thus, a comprehensive understanding of the lives of chronically ill individuals by health care providers, in the context of their psychosocial adjustment to chronic illness, may help to provide insight into their difficulty with negotiating the adjustment process in order to try and circumvent negative adaptational outcomes.

The present study also highlighted the importance of understanding participants' views regarding their social support and social interaction, such as the

influence of social support on self-identity and perceptions of independence, which can also impact on their willingness to receive support when needed. One participant's perception that support from others was devoid of empathy suggests that he felt alone with his chronic illness despite the presence of support, which also suggests that the quality of support received was important to him. While social interactions were perceived to be generally positive in this study, there were also negative views in some cases. It therefore seems important for health care services to understand and address issues relating to the significance of social support and social interaction for individuals with chronic illness given that it has the potential to influence their mental health and quality of life. Health care services may be able to address these issues by targeting patients' beliefs regarding their social support and social interactions, or by exploring patients' current social networks with the aim of improving the quality of their social support and social interactions.

With one possible exception (Anthony), and in accordance with English Proficiency (2006, cited in Greek Care, 2013b), it is likely that the English language proficiency for the remaining study's participants, one aged 69 and the remaining aged 70 and above, was not well advanced. According to Greek Care (2013e), this is partly due to this population's tendency to revert to their first language (i.e. Greek) with advanced age. Nonetheless, it is possible that an underdeveloped English language proficiency may not have been a major concern for this group of participants given that they developed and maintained social contacts with others in their Greek community since arriving from their homeland (i.e. Greece) in the 1950's and 1960's (Greek Care, 2013f), which may have also helped to buffer them from feeling isolated. Some of the participants also appeared to establish relationships with doctors of a similar ethnic background. For instance, two participants indicated that they had

Greek doctors, which suggests that they may have overcome the language barrier by seeking out a doctor who spoke the same language. However, it was uncertain if the remaining participants had done the same. Thus, despite their possibly underdeveloped English language proficiency, seeking out a Greek doctor is also likely to have facilitated communication and discussion of participants' illness experience with their doctor.

Social constructionism, the epistemological approach adopted for this study, is concordant with the view that individuals are active rather than passive contributors to their illness experience by providing it with meaning that takes into account contextual (social, cultural) influences impinging on their illness experience (Conrad & Barker, 2010). The researcher was also more guided by Braun & Clarke's (2006) arguments about thematic analysis which seeks "to theorize the sociocultural contexts, and structural conditions, that enable the individual accounts that are provided" (Braun & Clarke, 2006, p. 85), which also facilitated the combination of inductive and deductive analyses. Furthermore, individuals' narratives may also have implications for clinical practice given that their inclusion in the doctor-patient relationship may help to improve medical professionals' treatment towards their patients that takes into account patients' illness experience which is also shaped by their socio-cultural context (Conrad & Barker, 2010).

### **The Researcher's Experience of the Study**

What stood out for the researcher from the findings was the stark contrast in the experience of chronic illness between one participant (Michael) and the remaining participants. In particular, given the researcher's own preconceptions regarding the general reticence of elderly Greek-speaking males to disclose their feelings prior to this study, a masculinity issue which may also extend beyond the Greek community,



he was surprised by Michael's openness in communicating his negative feelings (despair, low self-worth, depressed mood) following his life event stress (loss of business and house), and his subsequent experience with illness (chronic obstructive pulmonary disease), that permeated every facet of his life, making him appear as if he was waiting to die. The researcher was also surprised by another participant, Bill, who appeared to be more open than other participants in talking about his vulnerabilities and expressing his emotions (anxiety, sadness) regarding his experience with chronic illness (end-stage kidney disease), who nonetheless appeared to be managing his illness. Thus in comparison to the other participants, it appears that Bill and Michael were able to openly express their feelings. On the one hand, it may be that this difference was attributable to their emotional responses in relation to the disruption associated with adversity (Bury, 1982), in this case chronic illness. Alternatively, perhaps this difference was associated with participants' different attitudes towards their chronic illness that may have also been influenced by their advanced age as well as their life experience (Pound, 1998; Williams, 2000).

What the researcher found particularly challenging was his interview with another participant, Gerry, who appeared to be critical and developed a negative view of the researcher during interviewing after the researcher misunderstood Gerry's attempt to pronounce the word 'impotence' in English. Rapport could not be re-established with Gerry who subsequently requested to end the interview a short time later. On one level, the researcher felt somewhat guilty that his misunderstanding led to this situation. Yet upon reflection, the researcher also felt that Gerry's behaviour may have been related, in part, to his difficulty in discussing his vulnerabilities in this sensitive area, which may have been partly influenced by language difficulties. Moreover, through his interview experience with Gerry, the researcher also thought

about what it might have been like for these Greek individuals, for whom English was not their first language, to communicate their vulnerabilities regarding their experience with chronic illness in situations where they relied on English-speaking doctors.

The researcher also found it interesting working within the CSM, particular the variation in the relationships between participants' beliefs and behaviours that became evident from the findings. For example, Anthony's beliefs about his illness and the marked contrast with the reality of managing his illness that differed from Bill's beliefs and their general concordance with his behaviour and management of his illness. The researcher was also impressed by the extent to which most of the participants were able to adjust to their chronic illness by finding a sense of meaning and pursuing goals that also gave them a sense of purpose in life (e.g. life satisfaction, appreciation in life, enhancing interpersonal relationships), despite their experience with adversity (chronic illness).

### **Recommendations for Further Research**

Regarding recruitment through the Greek clubs, future research may benefit from the distribution of flyers to Greek male club members that include an invitation for male club members to fill in and return their contact details, provided they give consent, from a cut-out section of the flyer and placed in a box in the club rooms for the researcher to pick up on a return visit to each club. This may potentially help participants to preserve their identity in front of other members without divulging their interest in participating in the study. Also, planning for the inclusion of participants' partners in future researcher may add to and further enrich the contextual understanding of participants' experience of chronic illness.

The differences between participants regarding the discordance (or concordance) between their illness representations and their methods of coping and outcomes raised interesting questions regarding the possible mediating role of expectancies and motivation as well as self-efficacy between their beliefs and their actions. These mediating factors may have potentially contributed to differences in chronic illness management regarding adherence to treatment regimen and self-management requirements. The study also highlighted that contextual (social and cultural) factors, such as Greek hospitality, appeared to be influential in chronic illness management, as well as potentially influencing patients' passivity and unconditional compliance in the doctor-patient relationship. Future research may benefit from studying the mediating role of these factors on chronic illness management, which may contribute towards a better understanding of the processes that result in individual differences in the management of chronic illness, including individuals from different cultural backgrounds. Exploring the importance of emotion regulation for the control of chronic illness above other areas of chronic illness management is also another area of interest for future research.

The study also highlighted differences between individuals' psychosocial adjustment to their chronic illness. In particular, cultural influences relating to fate and luck, which are not limited to the Greek culture, as well as the impact of stressful life events and their influence on psychosocial adjustment outcomes. Further research in these areas may help to facilitate an understanding of their role on psychosocial adjustment to chronic illness. Regarding social support, further investigation of the negative influence of external support (e.g. professional care) may be warranted given its impact on views of independence and stigma and the potential impact on chronically ill individuals' ability to receive such support when actually needed.

Differences in psychosocial outcomes for chronically ill individuals with and without social interaction may warrant further exploration in relation to the influence of social interaction on negative psychosocial outcomes.

## **Conclusion**

This study explored themes regarding Greek-speaking males' experience of chronic illness, in particular themes relating to their illness representations and coping procedures based on the Common Sense Model (CSM) of the self-regulation of health and illness (Leventhal et al., 2003). The present study also explored themes relating to this group's psychosocial adjustment to their chronic illness as well as themes on social influences (social support and social interaction) and their influence on participants' experience with chronic illness. Findings on the CSM themes answered the research questions, as did the psychosocial and social influence themes.

Implications of the findings include the importance of identifying and evaluating patients' beliefs and perceptions (illness representations), including any socio-cultural influences, relating to their chronic illness experience that may influence their health and illness behaviours (coping procedures), including differences in their illness representations and the reality of managing their chronic illness (coping procedures). Findings also provide some insight into possible mediating influences (expectancies, motivation, self-efficacy, socio-cultural influences) that may contribute to individual differences between this cultural group's chronic illness representations and their coping procedures, which also formed recommendations for further research. Further recommendations include the exploration of socio-cultural influences and significant life events that may influence psychosocial adjustment to chronic illness.

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APPENDIX A

APPROVAL OF ETHICS APPLICATION





APPENDIX A      Approval of Ethics Application

# MEMO

TO            Dr. Denise Charman  
                School of Psychology  
                St Albans Campus

DATE        03/12/2007

FROM        Dr. David Sornig  
                Acting Chair  
                Faculty of Arts, Education & Human Development  
                Human Research Ethics Committee

SUBJECT    Ethics Application – HRETH 07/99  
T

Dear Dr. Charman,

Thank you for resubmitting this application for ethical approval of the project:

**HRETH07/99      Experience of Greek Males to Chronic Illness.**

The proposed research project has been accepted by the Acting Chair, Arts, Education & Human Development Human Research Ethics Committee. Approval for this application has been granted from 03 December 2007 to 3 December 2009.

Please note that the Human Research Ethics Committee must be informed of the following: any changes to the approved research protocol, project timelines, any serious or unexpected adverse effects on participants, and unforeseen events that may effect continued ethical acceptability of the project. In these unlikely events, researchers must immediately cease all data collection until the Committee has approved the changes.

Continued approval of this research project by the Victoria University Human Research Ethics Committee (VUHREC) is conditional upon the provision of a report within 12 months of the above approval date (by **3 December 2008**) or upon the completion of the project (if earlier). A report proforma may be downloaded from the VUHREC web site at: <http://research.vu.edu.au/hrec.php>

If you have any queries, please do not hesitate to contact me on 9919 2584.

On behalf of the Committee, I wish you all the best for the conduct of the project.

**Dr. David Sornig**  
Acting Chair

**Faculty of Arts, Education & Human Development Human Research Ethics Committee**

APPENDIX B

INFORMATION TO PARTICIPANTS FORM

Πληροφορίες στους συμμετέχοντες**Η ΠΕΡΙΠΕΤΕΙΑ ΤΩΝ ΕΛΛΗΝΩΝ ΑΝΔΡΩΝ ΜΕ ΧΡΟΝΙΑ  
ΑΣΘΕΝΕΙΑ.**

Αγαπητέ Κύριε

Σας ευχαριστώ για την ώρα σας να διαβάσετε αυτό το φύλλο πληροφοριών. Ελπίζουμε ότι είστε πρόθυμοι να συμμετέχετε σε αυτήν την έρευνα, η οποία προσπαθεί να εξετάσει την περιπέτεια του Έλληνα άνδρα μετανάστη με χρόνια ασθένεια, μαζί με οποιεσδήποτε αντιδράσεις και προσαρμογές στην ασθένεια.

Είμαι ο Στάθης Αλεξίου, και σπουδάζω ψυχολογία (κλινική ψυχολογία) στο πανεπιστήμιο Victoria University. Ο επόπτης μου είναι ο Dr. Christopher Sonn. Θέλω να σας προσκαλέσω να συμμετέχετε σε αυτό το ερευνητικό πρόγραμμα που συμπληρώνεται ως τμήμα των μελετών μου. Ένας σκοπός αυτού του προγράμματος είναι να ερευνηθεί η περιπέτεια της χρόνιας ασθένειας μεταξύ των Ελλήνων ανδρών μεταναστών που ζουν στην Αυστραλία. Ένας δεύτερος σκοπός είναι να εξερευνηθούν αντιδράσεις και προσαρμογή των Ελλήνων ανδρών μεταναστών στη χρόνια ασθένεια.

Εάν συμφωνήσετε να συμμετέχετε, θα σας ζητήσουμε να απαντήσετε διάφορες ερωτήσεις σχετικά με την υγεία σας και να προσφέρετε μερικές δημογραφικές λεπτομέρειες. Θα σας παρακαλέσουμε επίσης να συμμετέχετε σε μια συνέντευξη στην οποία θα σας ζητήσουμε μερικές ερωτήσεις για την ασθένειά σας. Η συνεδρίαση θα βαστήξει περίπου 90 λεπτά, ανάλογα με τη διάρκεια των περιόδων ξεκούρασης.

Η συμμετοχή σας θα είναι εμπιστευτική και εθελοντική. Οι προσωπικές πληροφορίες σας δεν θα αποκαλυφθούν και έχετε το δικαίωμα να αποσύρετε την συμμετοχή σας σε αυτό το πρόγραμμα οποτεδήποτε. Εάν κάτι σου στεναχωράει, ο ερευνητής θα σας καθησυχάσει και θα σας ξανά-βεβαιώσει την εμπιστευτικότητά σας, και η συνέντευξη μπορεί να σταματήσει, εάν επιθυμείτε. Οι ερευνητές μπορούν να κανονίσουν μια ακόλουθη συνεδρίαση με σας, εάν συμφωνείτε. Οι ελεύθερες υπηρεσίες υποστήριξης Australian Greek Welfare Society Ltd. είναι διαθέσιμες σε σας (κοιτάξτε τις λεπτομέρειες που ακολουθούν) και μπορείτε να συμβουλευθείτε τον ιατρό παθολόγο ή τους συγγενείς σας και τους φίλους σας.

Australian Greek Welfare Society Ltd.  
7 Union Street, Brunswick  
Victoria, Australia, 3056  
Telephone: +61 (03) 9388 9998  
Facsimile: +61 (03) 9388 9992  
e-mail: [agws@agws.com.au](mailto:agws@agws.com.au)  
Website: [www.agws.com.au](http://www.agws.com.au)

Όλα τα αποτελέσματα θα αποθηκευτούν χρησιμοποιώντας τους αριθμητικά κρυπτογραφημένους κώδικες αρχείων για να διατηρήσουν την ανωνυμία. Όλα τα αποτελέσματα θα αναφερθούν ανώνυμα. Τα αγνώριστα αρχεία στοιχείων θα αποθηκευτούν με σύνθημα προφυλάξεις στους υπολογιστές που ανήκουν στη σχολή της ψυχολογίας, Victoria University για μια περίοδο 5 ετών μετά από την συμπλήρωση της μελέτης.

Σαν συμμετέχοντα μπορείτε να λάβετε μια περίληψη των ατομικών στοιχείων σας, εάν επιθυμείτε, με τηλεφώνημα στον αριθμό παρερχόμενο.

Οποιοσδήποτε ερωτήσεις σχετικά με αυτό το πρόγραμμα μπορούν να κατευθυνθούν στον εαυτό μου, Στάθης Αλεξίου, τηλέφωνο: 0419 361 991 ή στη σχολή της ψυχολογίας με ηλεκτρονικό ταχυδρομείο: [stan.alexiou@live.vu.edu.au](mailto:stan.alexiou@live.vu.edu.au). Αλλιώς, τηλεφωνήστε τον ερευνητικό επόπτη Christopher Sonn, της σχολής της ψυχολογίας στον αριθμό τηλεφώνου (03) 9919 5226, ή με ηλεκτρονικό ταχυδρομείο: [Christopher.Sonn@vu.edu.au](mailto:Christopher.Sonn@vu.edu.au)

Εάν έχετε οποιαδήποτε παράπονα ή ερωτήσεις ώστε ο ερευνητής δεν ήταν σε θέση να απαντήσει προς την ικανοποίησή σας, μπορείτε να έρθετε σε επαφή με το γραμματέα, Office for Research, Victoria, P.O. Box 14428MC, Melbourne 8001, ph: 9919 4710.

APPENDIX C

CONSENT FORM FOR PARTICIPANTS

## **ΦΟΡΜΑ ΣΥΓΚΑΤΑΘΕΣΗΣ ΓΙΑ ΤΟΥΣ ΣΥΜΜΕΤΕΧΟΝΤΕΣ ΠΟΥ ΣΥΝΕΠΑΓΟΥΝ ΣΤΗΝ ΕΡΕΥΝΑ**

### **ΠΛΗΡΟΦΟΡΙΕΣ ΣΤΟΥΣ ΣΥΜΜΕΤΕΧΟΝΤΕΣ:**

Θα επιθυμούσαμε να σας προσκαλέσουμε να λαμβάνετε μέρος μιας μελέτης περιλαμβάνοντας Έλληνες άνδρες πρώτης γενεάς και της εμπειρίας ασθένειάς τους.

Αυτή η έρευνα παρακαλεί το θέμα ποια υποστήριξη ή ειδικά υπάρχει για αυτές τις υποθέσεις για τους Έλληνες άνδρες πρώτης γενεάς και την εμπειρία τους ασθένειας και κοινωνικού πλαισίου. Ιδιαίτερα αυτή η μελέτη θα ερευνήσει πώς οι Έλληνες άνδρες πρώτης γενεάς που έχουν μια χρόνια ασθένεια δοκιμάζουν και αντιδρούν και προσαρμόζονται (ή όχι) στην ασθένειά τους.

### **ΠΙΣΤΟΠΟΙΗΣΗ ΑΠΟ ΤΟ ΣΥΜΜΕΤΕΧΟΝΤΑ**

Εγώ,  
διαμένοντας  
πιστοποιώ ότι είμαι τουλάχιστον 18 ετών και ότι δίνω εθελοντικά τη συγκατάθεσή μου για να συμμετέχω στη μελέτη: **Η Περιπέτεια των Ελλήνων ανδρών με χρόνια ασθένεια** διευθυμένος στο Victoria University από τον Στάθη Αλεξίου (ερευνητής σπουδαστών) και των Dr. Christopher Sonn (ερευνητικός επόπτης).

Πιστοποιώ ότι οι σκοποί της μελέτης, μαζί με οποιουδήποτε κινδύνους και μέτρα προστασίας που συνδέονται με τις διαδικασίες που απαριθμούνται κάτωθι και θα πραγματοποιηθούν στην έρευνα, έχουν εξηγηθεί πλήρως σε μένα και έχω λάβει ένα αντίγραφο των πληροφοριών στους συμμετέχοντες, από τον:

Στάθη Αλεξίου

και ότι συμφωνώ ελεύθερα με τη συμμετοχή που περιλαμβάνει τη χρήση μου σε αυτών των διαδικασιών:

- Να Ολοκληρώσω ένα μικρό δημογραφικό ερωτηματολόγιο
- Να Ολοκληρώσω ερωτηματολόγια σχετικά με την υγεία και την ευημερία

- Να Συμμετέχω σε μια συνέντευξη που θα είναι μαγνητοφωνημένη

Πιστοποιώ ότι είχα την ευκαιρία να μου δώσετε απαντήσεις σε οποιεσδήποτε παρουσιασμένες ερωτήσεις και επίσης καταλαβαίνω ότι μπορώ να αποσύρω από αυτήν την μελέτη οποιαδήποτε στιγμή και ότι αυτή η απόσυρση δεν θα με διακινδυνεύσει με κανένα τρόπο.

Έχω ενημερωθεί ότι οι πληροφορίες που παρέχω θα κρατηθούν εμπιστευτικές.

Υπογραφή:

Ημερομηνία:

Οποιοσδήποτε ερωτήσεις για τη συμμετοχή σας σε αυτό το πρόγραμμα μπορούν να κατευθυνθούν στους ερευνητές, τον Στάθη Αλεξίου ή των Dr. Christopher Sonn, pH. 9919 5226. Εάν έχετε οποιεσδήποτε ερωτήσεις ή παράπονα για τον τρόπο που έχετε Φερθεί, μπορείτε να έρθετε σε επαφή με το γραμματέα, Office for Research, Victoria, P.O. Box 14428MC, Melbourne 8001, ph: 9919 4710.

APPENDIX D

DEMOGRAPHIC DATA FORM



**Δημογραφικά στοιχεία**

Ηλικία: .....

Ταχυδρομικός τομέυς: .....

Ποια περιοχή της Ελλάδος έζησες:

Έθνος: Έλληνας; Έλληνο-Αυστραλός; Αυστραλός;  
Άλλως, παρακαλώ διευκρινίστε  
.....

Θρησκεία: .....

Τύπος εκπαίδευσης : 1. Καθόλου, δεν πήγα στο σχολείο  
2. Δημοτικό σχολείο, δεν τελείωσα  
3. Δημοτικό σχολείο, τελείωσα  
4. Γυμνάσιο, δεν τελείωσα  
5. Γυμνάσιο, τελείωσα

Συζυγική κατάσταση: .....

Πόσα παιδιά έχεις: ..... Γένος και ηλικίες: .....

Εκτεταμένα οικογενειακά μέλη στο σπιτικό: .....

Συγγένεια: .....

Εργατική κατάσταση: Επίδομα; Συνταξιούχος; Τύπος εργασίας;  
Κάποτε ή Τακτικά;  
Εάν δουλεύεις, ποια είναι η εργασία σου; .....

Ετήσιο εισόδημα: 0 έως \$20,000 \$21,000 έως \$30,000 \$31,000 έως  
\$40,000 \$41,000 έως \$50,000 \$51,000 έως \$60,000; περισσότερο  
από \$61,000. Καμία απάντηση.

## APPENDIX E

### RAND 36-ITEM HEALTH SURVEY 1.0 QUESTIONNAIRE (RAND SF-36)

**36 στοιχεία ερωτηματολογίων ερευνών υγείας 1.0**

1. Γενικά, θα ελέγατε η υγεία σας είναι:	
Άριστη	1
Πολύ καλή	2
Καλή	3
Δίκαια	4
Φτωχή	5

2. <b>Εάν συγκρίνετε με ένα χρόνο πριν</b> , πώς θεωρείτε την υγεία σας γενικά <b>τώρα</b> ;	
Πολύ καλύτερα τώρα από ένα χρόνο πριν	1
Κάπως καλύτερα τώρα από ένα χρόνο πριν	2
Σχεδόν ίδια	3
Κάπως χειρότερα τώρα από ένα χρόνο πριν	4
Πολύ χειρότερα τώρα από ένα χρόνο πριν	5

Τα ακόλουθα στοιχεία είναι για τις δραστηριότητες που μπορεί να κάνετε κατά τη διάρκεια μιας χαρακτηριστικής ημέρας. Η υγεία σας σας περιορίζει τώρα σε αυτές τις δραστηριότητες; Σε κάθε περίπτωση, πόσο;

**(Διάγραφε κύκλο γύρο ένα αριθμό σε κάθε γραμμή)**

	Ναι, περιορισμένος πολύ	Ναι, περιορισμένος λίγο	Όχι, περιορισμένος καθόλου
3. <b>Ενεργητικές δραστηριότητες</b> , όπως το τρέξιμο, σήκωμα βαριά πράγματα, συμμετέχοντας σε κουραστικό αθλητισμό	[1]	[2]	[3]
4. <b>Μέτριες δραστηριότητες</b> , όπως η κίνηση ενός τραπεζιού, σπρώχνοντας μια ηλεκτρική σκούπα, μπόουλινγκ, ή παίζοντας γκολφ	[1]	[2]	[3]
5. Σήκωμα ή κρατώντας παντοπωλεία	[1]	[2]	[3]
6. Ανεβαίνοντας <b>αρκετές</b> σειρές σκαλοπατιών	[1]	[2]	[3]
7. Ανεβαίνοντας <b>μια</b> σειρά σκαλοπατιών	[1]	[2]	[3]
8. Λυγίζοντας, γονατίζοντας, ή Σκύβοντας	[1]	[2]	[3]
9. Περιπάτημα <b>περισσότερο από ένα μίλι</b>	[1]	[2]	[3]
10. Περιπάτημα <b>μερικά τετράγωνα</b>	[1]	[2]	[3]
11. Περιπάτημα <b>ένα τετράγωνο</b>	[1]	[2]	[3]
12. Πλένοντας ή ντύνοντας τον εαυτό σου	[1]	[2]	[3]

Στους **περασμένες 4 εβδομάδες**, έχετε οποιαδήποτε από τα ακόλουθα προβλήματα με την εργασία σας ή άλλες κανονικές καθημερινές δραστηριότητες **σαν αποτέλεσμα την φυσική υγεία σας;**

**(Διάγραφε κύκλο γύρο ένα αριθμό σε κάθε γραμμή)**

	Ναι	Όχι
13. Περιορίστε το χρονικό διάστημα που ξοδέψατε στην εργασία ή άλλες δραστηριότητες	1	2
14. <b>Καταφέρατε λιγότερα</b> από ότι θέλατε	1	2
15. Περιορίσατε σε <b>είδος</b> εργασία ή άλλες δραστηριότητες	1	2
16. Είχατε <b>δυσκολία</b> να εκτελέσετε την εργασία ή άλλων δραστηριοτήτων (παραδείγματος χάριν, χριζόντανε περισσότερη προσπάθεια)	1	2

Στους **περασμένες 4 εβδομάδες**, σας έχει οποιαδήποτε από τα ακόλουθα προβλήματα με την εργασία σας ή άλλες κανονικές καθημερινές δραστηριότητες **σαν αποτέλεσμα οποιαδήποτε συναισθηματικά προβλήματα** (όπως να αισθάνεστε κατάθλιψη ή ανήσυχος);

**(Διάγραφε κύκλο γύρο ένα αριθμό σε κάθε γραμμή)**

	Ναι	Όχι
17. Περιορίστε <b>χρονικό διάστημα</b> που ξοδέψατε στην εργασία ή άλλες δραστηριότητες	1	2
18. <b>Καταφέρατε λιγότερα</b> από ότι θέλατε	1	2
19. Δεν κάνετε εργασία ή άλλες δραστηριότητες τόσο <b>προσεκτικά</b> όπως συνήθως	1	2

20. Στους **περασμένες 4 εβδομάδες**, μέχρι ποιου βαθμού σας έχει εμποδίσει η φυσική υγεία ή τα συναισθηματικά προβλήματά σας με τις κανονικές κοινωνικές δραστηριότητές σας με την οικογένεια, τους φίλους, τους γείτονες, ή τις ομάδες;

**(Διάγραφε κύκλο γύρο ένα αριθμό)**

Καθόλου	1
Λίγο	2
Μέτρια	3
Αρκετά	4
Πάρα Πολύ	5

21. Πόσο **σωματικό** πόνο είχες στους **περασμένες 4 εβδομάδες**;

**(Διάγραφε κύκλο γύρο ένα αριθμό)**

Καθόλου	1
Πολύ μαλακό	2
Μαλακό	3
Μέτριο	4
Σοβαρό	5
Πολύ σοβαρό	6

22. Στους **περασμένες 4 εβδομάδες**, πόσο σας έχει εμποδίσει ο **πόνος** με την κανονική εργασία σας (συμπεριλαμβάνοντας εργασία έξω του σπιτιού και επίσης τοις δουλειές του σπιτιού);

**(Διάγραφε κύκλο γύρο ένα αριθμό)**

Καθόλου	1
Λίγο	2
Μέτρια	3

Αρκετά 4

Πάρα Πολύ 5

Αυτές οι ερωτήσεις ενδιαφέρουν πώς αισθάνεστε και πώς ήταν τα πράγματα με σας **στους περασμένες 4 εβδομάδες**. Για κάθε ερώτηση, παρακαλώ δώστε τη μια απάντηση που έρχεται πιο κοντά στον τρόπο που έχετε αισθανθεί.

Πόσο καιρό στους **περασμένες 4 εβδομάδες** . . .

**(Διάγραφε κύκλο γύρω ένα αριθμό σε κάθε γραμμή)**

	Πάντα	Ο περισσότερος καιρός	Αρκετός καιρός	Μερικός καιρός	Λίγος καιρός	Καθόλου
23. Αισθανθήκατε γεμάτο κέφι;	1	2	3	4	5	6
24. Είστε πολύ νευρικός άνθρωπος;	1	2	3	4	5	6
25. Έχετε αισθανθεί τόσο άκεφοι που τίποτα δεν θα μπορούσε να σας χαροποιήσει;	1	2	3	4	5	6
26. Έχετε αισθανθεί ήρεμοι και ειρηνικοί;	1	2	3	4	5	6
27. Είχατε πολύ ενέργεια;	1	2	3	4	5	6

	Πάντα	Ο περισσότερος καιρός	Αρκετός καιρός	Μερικός καιρός	Λίγος καιρός	Καθόλου
28. Έχετε αισθανθεί κακόκεφοι και μελαγχολία;	1	2	3	4	5	6
29. Αισθανθήκατ ε εξαντλημένο ι;	1	2	3	4	5	6
30. Ήσασταν ευτυχισμένοι ;	1	2	3	4	5	6
31. Αισθανθήκατ ε κουρασμένοι ;	1	2	3	4	5	6

32. Στους **περασμένες 4 εβδομάδες**, πόσο καιρό έχει εμποδίσει η **φυσική υγεία σας ή τα συναισθηματικά προβλήματα** σας με τις κοινωνικές δραστηριότητές σας (όπως την επίσκεψη με τους φίλους, τους συγγενείς, κ.λπ.);

**(Διάγραφε κύκλο γύρω ένα αριθμό)**

Πάντα	1
Ο περισσότερος καιρός	2
Μερικός καιρός	3
Λίγος καιρός	4
Καθόλου	5



Πόσο ΑΛΗΘΙΑ ή ΨΕΥΤΙΚΑ είναι η κάθε μία από τις ακόλουθες δηλώσεις για σας.

**(Διάγραφε κύκλο γύρω ένα αριθμό σε κάθε γραμμή)**

	Σίγουρα αλήθεια	Συνήθως αλήθεια	Δεν ξέρω	Συνήθως ψεύτικα	Σίγουρα ψεύτικα
33. Φαίνομαι να αρρωσταίνω λίγο πιο εύκολα από άλλους ανθρώπους	1	2	3	4	5
34. Είμαι τόσο υγιής ως οποιονδήποτε που ξέρω	1	2	3	4	5
35. Υποθέτω να χειροτερέψει η υγεία μου	1	2	3	4	5
36. Η υγεία μου είναι υπέροχη	1	2	3	4	5

# RAND SF-36: Greek to English translation

**Chris Sardelis English Translations**

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TRANSLATED FROM	REGISTRATION NUMBER	YEAR
GREEK	NAATI 3677	2009

## TRANSLATION OF A HEALTH QUESTIONNAIRE

### 36 items of health research questionnaire 1.0

1. In general, would you say your health is:

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. If you compare to one year ago,  
how would you rate your health in general now?

Much better now than a year ago	1
Somewhat better now than a year ago	2
About the same	3
Somewhat worse now than a year ago	4
Much worse now than a year ago	5

The following items are about activities you might do during a usual day. Does **your health now limit you** in these activities? In any case how much?

(Make a Circle on One Number on Each Line)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
3. Vigorous activities, such as running, lifting heavy objects,	[1]	[2]	[3]



participating in insistent sports			
4. <b>Moderate activities</b> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	[1]	[2]	[3]
5. Lifting or carrying groceries	[1]	[2]	[3]
6. Climbing <b>many</b> flights of stairs	[1]	[2]	[3]
7. Climbing <b>one</b> flight of stairs	[1]	[2]	[3]
8. Bending, kneeling, or stooping	[1]	[2]	[3]
9. Walking <b>more than a mile</b>	[1]	[2]	[3]
10. Walking <b>several blocks</b>	[1]	[2]	[3]
11. Walking <b>one block</b>	[1]	[2]	[3]
12. Bathing or dressing yourself	[1]	[2]	[3]

In the **past 4 weeks**, have you got any of the following problems with your work or other regular daily activities **as a result of your physical health?**

(Circle One Number on Each Line)

	Yes	No
13. Reduced the amount of time you spent on work or other activities	1	2
14. <b>Accomplished less</b> than you would like	1	2
15. Reduced the <b>type</b> of work or other activities	1	2
16. Had <b>difficulty</b> performing the work or other activities (for example, more effort needed)	1	2



During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

(Circle One Number on Each Line)

	Yes	No
17. Cut down the <b>amount of time</b> you spent on work or other activities	1	2
18. <b>Accomplished less</b> than you would like	1	2
19. Didn't do work or other activities as <b>carefully</b> as usual	1	2

20. In the **past 4 weeks**, to what degree has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

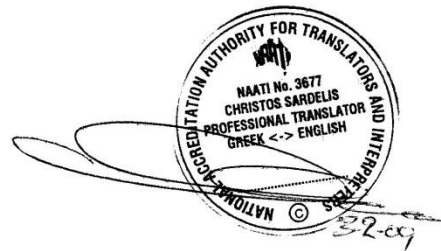
(Circle One Number)

- Not at all 1
- Little 2
- Moderately 3
- Enough 4
- Extremely 5

21. How much **bodily** pain have you had in the **past 4 weeks**?

(Circle One Number)

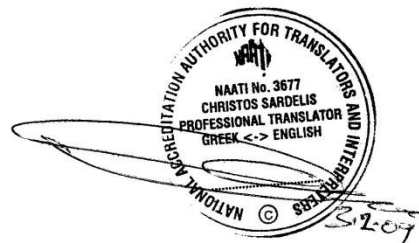
- None 1
- Little 2
- Moderate 3
- Enough 4
- Extreme 5
- Very severe 6



22. In the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

**(Circle One Number)**

- Not at all 1  
A little 2  
Moderately 3  
Enough 4  
Extremely 5



These questions refer to how you feel and how things have been with you **in the past 4 weeks**. For each question, please give the one answer that comes nearer to the way you felt.

How much of the time during the **past 4 weeks** . . .

**(Circle One Number on Each Line)**

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of energy?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so cheerless that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt sad and melancholic ?	1	2	3	4	5	6
29. Did you feel exhausted?	1	2	3	4	5	6
30. Are you a happy	1	2	3	4	5	6

person?						
31. Did you feel tired?	1	2	3	4	5	6

32. In the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

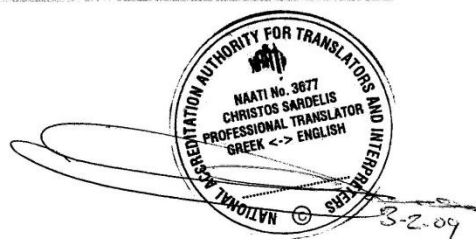
**(Circle One Number)**

- Always 1  
Most of the time 2  
Some of the time 3  
Few times 4  
Never 5

How TRUE or FALSE is each of the following statements for you.

**(Circle One Number on Each Line)**

	Definitely True	Usually True	I don't Know	Usually False	Certainly False
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I suppose my health will get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5



Changes made to RAND SF-36 Greek version following back translation from Greek to English

Table E1

*Changes Made to RAND SF-36 Greek Version Following Back Translation From Greek to English*

Rand SF-36 Item No.	Original	Back-Translation	Greek Original	Greek Revision
3	“.....participating in strenuous sports”	“.....participating in insistent sports”	συμμετέχοντας σε επίμονο αθλητισμό”	“..... συμμετέχοντας σε κουραστικό αθλητισμό ”
30	“Have you been a happy person?”	“Are you a happy person?”	Είστε ευτυχισμένος άνθρωπος;	Ήσασταν ευτυχισμένοι;

APPENDIX F

SEMI-STRUCTURED INTERVIEW QUESTIONS FOR

PARTICIPANTS



Version

## **Common-Sense Model of Illness Representation (CSM)**

Illness dimensions (identity, cause, consequences, timeline, control)

- Can you tell me about your illness?
  - Description(s)
  - Symptoms <identity>
  - Cause
  - Onset
  - Consequences
  - Duration (timeline)
  - Progress (episodic (periodic) or cyclic)
  - Control
  - Treatment

Affect

- Could you talk about any emotional distress that you have experienced in having your illness?
  - Description (of distress)
  - Reason (for distress)

Self-Regulation

- What have you done to help manage/alleviate the symptoms of [*your illness*]?

## **Coping Style and Strategies**

- What do you do when you are faced with stressful situations?
- How did you cope with [*your illness*] when you first learned about it?
- How do you cope with [*your illness*] these days?

## **Psychosocial Adaptation**

- How did you react when you first experienced [*your illness*]?
  - Early reactions
- How have you felt about [*your illness*] since you first experienced it?
  - Intermediate reactions
  - Later reactions

## **Psychological Growth and Benefit Finding**

- How has [*your illness*] affected the way you view yourself?
- How has [*your illness*] affected the way you relate to other people?
- How has [*your illness*] affected the way you look at life?
- What have you gained as a result of having [*your illness*]?

## **Socio-Cultural Factors**

### Masculinity and Identity

- How did you view yourself, and your role in life, prior to your illness?
- How did [*your illness*] affect your view of yourself, and your role in life?
- How do you view your illness?

### Childhood experiences of illness and Cultural Health Beliefs and Practices

- Can you tell me about you and your family's experience of illness when you were growing up as a child?
- Can you tell me about any traditional beliefs and ways to provide health?

### Migration/Acculturation

- Can you tell me about your way of life in [*your homeland*] before coming to Australia?
- How did you adapt to the Australian way of life after arriving in Australia?
- How would you describe your way of life now compared with when you first arrived in Australia?
- How would you compare your way of life in Australia with your way of life in [*your homeland*]?

### Social Support

- How have you been supported through your illness?
- Can you tell me more about how [*others*] have supported you through your illness?
- What is it like for you having social support?
- What social interaction have you had with others?
- What is it like having social interaction?
- What other activities have you used to help you with your illness? Please explain.

### **Health Management**

- Can you tell me about your experience with health providers?

## **Πρότυπο κοινής λογικής της αντιπροσώπευσης ασθένειας (CSM)**

Διαστάσεις ασθένειας (ταυτότητα, αιτία, συνέπειες, υπόδειξη ως προς το χρόνο, έλεγχος)

- Μπορείτε να μου πείτε για την αρρώστια σας;
  - Περιγραφή
  - Ταυτότητα <συμπτωμάτων>
  - Αιτία
  - Αρχή
  - Συνέπειες
  - Διάρκεια (υπόδειξη ως προς το χρόνο)
  - Πρόοδος (επεισοδιακή (περιοδικός) ή κυκλική)
  - Έλεγχος
  - Θεραπεία

## Συναισθήματα

- Θα μπορούσατε να μιλήσετε για οποιεσδήποτε συναισθηματικές δυσκολίες που έχετε δοκιμάσει με την αρρώστια σας;
  - Περιγραφή (της δυσκολίας)
  - Λόγος (για την δυσκολία)

## Αυτορύθμιση

- Τι έχετε κάνει να σας βοηθήσει να καταφέρετε τα συμπτώματα της αρρώστιας σας;

### **Αντιμετωπίζοντας ύφος και στρατηγικές**

- Τι κάνετε όταν αντιμετωπίζετε αγχωτικές καταστάσεις;
- Πώς τα βγάζετε πέρα με [την αρρώστια σας] όταν πρωτάρχισε; >
- Πώς τα βγάζετε πέρα με [την αρρώστια σας] τώρα;

### **Ψυχοκοινωνική προσαρμογή**

- Πώς αντιδράσατε [την αρρώστια σας] όταν την δοκιμάσατε στις αρχές?
  - Πρόωρες αντιδράσεις
- Πώς αισθανθήκατε για [την αρρώστια σας] από της αρχές μέχρι τώρα;
  - Ενδιάμεσες αντιδράσεις
  - Ποιο πρόσφατες αντιδράσεις

### **Ψυχολογική εύρεση αύξησης και οφελών**

- Πώς έχει επηρεάσει [η αρρώστια σας] τον τρόπο που εξετάζετε των εαυτών σας;
- Πώς έχει επηρεάσει [η αρρώστια σας] τον τρόπο που έχετε σχέσεις με άλλους ανθρώπους;
- Πώς έχει επηρεάσει [η αρρώστια σας] τον τρόπο που εξετάζετε τη ζωή;

- Τι έχετε κερδίσει σαν αποτέλεσμα που έχετε [την αρρώστια]?

## **Κοινωνικοπολιτιστικοί παράγοντες**

### Ανδροπρέπεια και ταυτότητα

- Πώς εξετάξετε των εαυτών σας, και το ρόλο σας στη ζωή, πριν από την αρρώστια σας;
- Πώς επηρέασε [η αρρώστια σας] την γνώμη που έχετε για τον εαυτών σας, και το ρόλο σας στη ζωή;
- Πώς βλέπετε την αρρώστια σας;

### Εμπειρία παιδικής ηλικίας της ασθένειας και των πολιτιστικών πεποιθήσεων υγείας και πρακτικές

- Θα μπορούσατε να μου πείτε για την εμπειρία της αρρώστιας για σας και της οικογένειάς σας όταν μεγαλώνετε ως παιδί;
- Θα μπορούσατε να μου πείτε για οποιουσδήποτε παραδοσιακούς λαϊκές δοξασίες και τρόπους να προσφέρει υγεία;

### Μετανάστευση/ενσωμάτωση

- Μπορείτε να μου πείτε για τον τρόπο ζωής [στην πατρίδα σας] πριν να μεταναστεύετε στην Αυστραλία;
- Πώς προσαρμοστήκατε στον αυστραλιανό τρόπο ζωής μετά που μεταναστεύατε στην Αυστραλία;

- Πώς θα περιγράφατε τον τρόπο ζωής σας τώρα σε σύγκριση με όταν μεταναστεύσατε στην Αυστραλία;
- Πώς θα συγκρίνατε τον τρόπο ζωής σας στην Αυστραλία με τον τρόπο ζωής σας [στην πατρίδα]?

### Κοινωνική υποστήριξη

- Πώς έχετε υποστηριχθεί μέσω την αρρώστια σας;
- Μπορείτε να μου πείτε περισσότερο για το πώς [άλλοι] σας έχουν υποστηρίξει μέσω την αρρώστια σας;
- Πως είναι για σας να έχετε κοινωνική υποστήριξη;
- Ποια κοινωνική αλληλεπίδραση είχατε με άλλους;
- Πως είναι για σας να έχετε κοινωνική αλληλεπίδραση;
- Τι άλλες δραστηριότητες έχετε χρησιμοποιήσει για να σας βοηθήσουν με την αρρώστια σας; Παρακαλώ εξηγήστε.

### **Διαχείριση υγείας**

- Μπορείτε να μου πείτε για την εμπειρία σας με τους προμηθευτές υγείας;



APPENDIX G

RAW PARTICIPANT EXCERPTS FROM SEMI-STRUCTURED  
INTERVIEW TRANSCRIPTS

## APPENDIX G      Raw Participant Excerpts from Semi-Structured Interview

### Transcripts

*(Note 1: Single quotation marks in these excerpts refer to participants' use of English.*

*Note 2: Double quotation marks in these excerpts refer to participants' quotes)*

### **Illness Representations**

#### **Illness cause**

##### Michael

*Because I made a business and I lost it, and the bank took my house and sold it, and didn't have a house.*

*Those bring on whatever illnesses I had, and the cigarettes I smoked so much, about thirty years. It's that.*

*The illness is, it naturally came from the worry, and from those that I went through. The illness and everything do not get better.*

##### Harry

*Us, our body produces them. I don't produce them.*

*Just like the car, the engine breaks down, and other things break down, that's how a person is, the engine, and a person's bodily system is an engine, like the car, and so like damage to the spark plugs when they don't get oiled, like another thing, that's how a person's engine is, when his rheumatism bothers him.*

*Because the age passes, like the car, as its age passes, everything, everything damages and that's how a person's engine is.*

Anthony

*Look, 'every', 'they reckon', [interviewer], someone in the family '100 years back' had it, and they say that it originated from the father, not from the mother, my mother did not have sugar, but someone in her family could have had sugar, and it comes to me.*

Peter

*Ahh, what other by-products are there with the heart, it's the medicine, what we call 'stress', the 'stress' is inherited, what we talked about, ok? A big worry. It's 'stress', it's inherited.*

**The physical consequences of illness: Importance of routine**

Michael

*The breathing was hard. They gave me the oxygen for that reason.*

*Many times I feel them a lot, many times I don't feel them at all, but the oxygen is always three, four times a day. Without the oxygen, I cannot live.*

#### Bill

*Not good, not good because we said that it's something that occupies the everyday, and I know the situation with the kidneys will not pass now! I can't not do those things that they tell me, I have to do them, because if I don't do them, we said, I'm finished, because when the kidneys work 5, 6 percent, it's very serious.*

#### Anthony

*A great deal, yes, it's a bad illness, very shifty illness, extremely shifty illness, because you can test your blood. This morning it was 5, yesterday it was 11, the day before 13. It doesn't matter what you eat, it doesn't matter if I don't eat, 'still' if it is to show, the 'blood test' will show it straight away, understand?*

*I have tried more, but when the more happens, I am worse off than normal. I feel it straight away. I might collapse, or if I'm not careful and I don't eat three times in the morning at different periods, the sugar will fall to '.2', in which case I might 'collapse' into a 'coma'. I have had it happen twice. Twice I went to the hospital.*

### **The physical consequences of illness: Impact on physical activity**

#### Peter

*When we walk, running, I can't, at the 10, of course, we will feel pain, we will swell up, we will stop, we can't lift weights, we can't bend down, in other words, I bend*

*down, but we said you can't bend down to work, to lift weights, many alternatives are not possible with a, with a heart operation.*

*You can't go and do work, in other words, in other words to lift, to bend down, to lift yourself up [raise yourself], whatever, whatever, and not even, let's say, to develop 'stress', to be seated on the chair and to start smoking, and whatever else, because that is also work. Not one thing or the other. The cardiac [system] should not overwork.*

*Many involving those went out of necessity for work, and they ceased in their work.*

#### Bill

*The consequences are sufficiently big. I don't have the, how do we say, I don't have the facility of the body to react. I'm not able to work with others. I have that issue.*

#### Peter

*You feel that you are a cardiac, worn out by the heart.*

#### Bill

*You worry, because we said that when a person is well, he's strong, but when he starts to get ill, by the way, we said, as we also said before, I'm reaching 80, consequently everything comes, and when they come, they don't leave easily, they don't leave, whatever it is, and more so the kidneys.*

Harry

*With age, man experiences a lot because the body wears out, that's why. There doesn't exist a person who lives beyond 70. I don't know, look, someone who doesn't have pressure, who doesn't have cholesterol, who doesn't have bad illnesses.*

**The psychological consequences of illness: Cravings**

Michael

*I had to stop smoking and its three weeks since I last smoked. I crave it but I cannot smoke it.*

Anthony

*I have, I have a weakness, I like to eat something, I like to grab something which is sweet. I want it and I can't, or I grab it and I become ill, one of the two.*

*With a little 'patience', and with some caution, in whatever I grab, like I told you before, in whatever I eat. I always make the mistake and eat more [than I should]. I like to eat. I go through that each day, the same routine. I can't do anything else. That's it.*

**The psychological consequences of illness: The importance of self-control**

Bill

*Salt is prohibited, the salt.*

*Very little water, I'm allowed one litre a day.*

*No Feta cheese at all, because of the salt.*

*The salty are not good. They are prohibited because the salty is, because it's water and the water is prohibited because the body accumulates fluids.*

*That's the everyday, that's the everyday. I'm thirsty, I'm thirsty, and I crave a glass of water, to enjoy it, to drink a lemonade, to drink something and, and I can't. If I drink, for example, half a glass of lemonade, I have to estimate how much of the day's total it is, so that I am 'about' on 1 litre. As a person, I also like to eat a nice meal, to drink a glass of beer, to drink a glass of water, I can't. [It's] difficult.*

### Anthony

*It needs a lot of attention, to know what you have, to know how you will get through it, even for a few minutes, in case you forget it, and from there onwards, you're 'okay', you're 'okay.' Or you shouldn't think about it all. Something that can't happen, it can't. Somewhere in the day you'll think, either from the walking, or your food, or from the medication you take, or something else that may happen, you immediately think that you don't feel well, and even if you are feeling well, you don't feel well. Understand? One affects the other.*

*It's not like drinking a glass of water, and drinking a glass of wine and say, "I won't think about the wine today, I'll think about it the day after tomorrow", I think about that every day. I can't say that when I get up in the morning, I won't find my 'medication' there. I can't see that the insulin does not exist. I can't see that there*

*isn't the 'injection' and I have to 'inject.' Understand? Therefore you think about it every day.*

*I can't even tell my wife I don't want to do the 'tests' today, because I don't like to do the tests. I have to do it to see where it is! Understand?*

### **The psychological consequences of illness: Emotional responses**

#### **Bill**

*Worry, because we said that when a person is healthy, he's healthy, but when a body starts to become ill, what else is there but worry.*

*Not good, not good, because you know that you have these things happen to you, you leave your life and you don't control it properly, you don't control it properly, and as much as it is, it creates worry in you, sadness in you.*

*Like a person who has proper kidneys that work properly compared with me who has damaged kidneys, that affects me a lot. The everyday, and the life, and the worry, and you might turn suddenly, might, might, might, 1000, 2 things, but we said, we can't do anything.*

*Tomorrow something might appear where I end up completely para, paralysed, where I won't be able to walk at all. It's something that I don't know.*



### Anthony

*I don't have it a lot of times. I have it when I have a little 'stress', in other words, something troubles me, or I learnt something from a friend, from a member of my family, eh, for one problem or another, or 'something goes wrong' with my children, with my children, you know, it's from those that I become easily troubled, and I say, "It's enough that I am ill, not him as well", understand?*

### Bill

*When a person's body becomes ill, whatever that is, it's a little serious. It's serious. Psychologically it causes sadness, you don't want to go anywhere, you don't want to move, you don't want to eat, your child or wife talks to you, you become abrupt, you become whatever, because it's something that they don't want, they don't want because we weren't the same before we became ill, we were people who worked, we looked after our children, our families, our houses, whatever, but now, when you become ill, you can't do anything. Even if you want to, you can't, even if you want to, you can't, you can't! Finished, finished, and whichever person says that they are happy in life when he is ill, he'll tell a lie, he'll tell a lie because we face situations, and it's the situations that bring on other things, and other, other, other which become a big mountain which presses down on us.*

### **The social consequences of illness: Concerns about others' reactions**

### Anthony

*I am a person, I always fall into the wrong, no matter how careful I am, I can't go to a table and sit, for you to 'offer' me something and for me to say I don't eat it or I*

*don't drink it because I have sugar. I'm embarrassed to say it and, forgetting that I'm not 'okay', I bite, but that which I bite, this [feeling biscuits on the table]...this is 'not bad', this is 'dry', it's ok, but something that is sweet, the 'bikkies', the sweets, those, they 'offer' you, a sweet on a teaspoon, I want it straight away, I crave it! The sugar asks for sugar, the 'diabetic' always asks for sugar, understand? And that's where I cop it, that happens.*

*I'll grab it, I want it, [and] I'll take it. When there is a familiar face that I recognise, I say, "You understand that I like it but it doesn't like me", 'I like it but it doesn't like me', understand? I don't want it, but when I sometimes go to a table with people who are strangers to me, I embarrass him and how will he take it?*

*It's affected me a lot because I can't, I go to a house for a visit. They say, "Bill, what will you drink, what can we serve you?" I want to drink a glass of beer, for example, to drink a glass of water, I can't and I avoid going for a visit because I notice that I make those people worry [about me].*

### **The social consequences of illness: Social comparisons**

#### **Peter**

*Like the other, my best man, who had it, it's not even, not even two weeks now, he said, "Wrong way." I said, "That's what the blockage is like", but I said to him "You'll surpass all of it because you are better than 'me'. You came out better, and younger, and so on. You escaped it earlier." Those are what offend us. He'll get over*

*it, like that, like that. I told my best man, “If I was like you, good.” I said, “That’s how it is.”*

### Spiro

*It affected [me]. When you are ill, it affected [me]. It affected [me] because you can’t do that which a healthy person can do. The healthy person jumps, dances, drinks, does, says his words, goes on trips wherever he wants. How can I make the trips that I want? ‘I’m scared’. Understand? How can it not affect me?*

### Anthony

*I have someone next to me, he goes to the toilet ‘five times’ and I drink my water and my wine, he doesn’t drink anything and runs to the toilet, I [don’t go] not even one time. ‘Thanks god’, you know what I mean? [laughing] and I tell you sometimes, sometimes ‘I feel good when I see others’ [laughing].*

*I don’t wish anyone to feel bad, you know?, but it relax me when I say, “Oh shit, he’s a younger, four years older, I don’t know, I don’t ask, I can’t ask”, but I feel good when he says to me, “‘Oh’, I’m going to the toilet again”, and I say to myself, “‘Five minutes ago’ he was there, the same thing again!, what’s happening to that person?”, and I say, “I sit here all this time and I don’t” [laughing].*

**Qualitative observations of participants' perceived health status (RAND SF-36)**  
**item responses in relation to health comparisons**

Peter

*What can I say, I already, it doesn't affect me now, I see myself extremely healthy like yourself now, okay, but I know, in other words, pale, in other words, that I am pale, that I have, and it is, but I feel very well like you. No difference, psychologically, psychologically, there isn't. Whatever there was has passed. Nothing can be repaired! Since it's not repairable, it's like that, I feel like you.*

*Rather well, rather well, in other words, I wish all the cardiac people to be 'excellent' like me. I really mean that. That all those operated on to feel like me. If they can find a way for the wheels to turn as I get by. I didn't have any complaint.*

**The social consequences of illness: Non-disclosure**

Spiro

*Look. It's not only people. I never speak about myself. When I am with other people, I don't behave as though I'm ill. I don't want them to feel sorry for me. I behave as if I am very 'healthy', as though I don't have anything. I laugh and talk. You know. I try. I don't want them to feel sorry for me. You know what happens if another person feels sorry for you? If another person feels sorry for you, you are finished. However, I want them to see me strong, my child! That's how I am. Nothing affects me at all. I have made up my mind that I don't want to drop my head at all. I want to hold my head up high.*

*I appear as if I'm not ill.*

Anthony

*With friends and relatives, of the many that don't know, I don't tell them anything. I don't tell them anything. The person I am [with them] is the person I want to remain. It's another matter if they find out about it, those that know already know, those that don't know will not learn about it. I will not say anything to anyone.*

*I don't like to worry them about my problem, my, what I have, my illness, for example. Maybe they'll get 'annoyed', understand? And they tell you, " 'We got our own', you keep them for yourself." I have learnt to be sincere, to not tell each person what I have, understand?*

*Look, the way I look at life based around my illness is as follows. To live each day that comes much better but not worse, and to feel more 'close' than I am in my house with my lot so that I am not affected by the thing, the idea that because I am ill, I make the rest ill, and so I try to always be a little 'firm', to have a 'profile' where I display 'happy' even if I'm not 'happy.'*

## **Treatment control: Reliance on medical professionals**

### Anthony

*The only treatment I follow is the doctors. They know. They tell me what I have to do. That's the treatment. There's no other treatment, only the 'medication' and the insulin.*

### Harry

*How are you going to cope? You'll go to the doctor. He'll give you the medication. What else do you do?*

*When the illness occurs, you don't know what you have. When you go to the doctor and you confirm and have an examination on what you have, and they give you the appropriate medication, I don't know, you become calm, you face the illness.*

*I don't have any problems, I don't have any problems with the illnesses, now I take the tablets, I take the others.*

### Spiro

*I believe in professionally qualified people, in doctors. I believe first in the doctors and then God, 'first the doctors and after the God.' I am 'very happy, no congratulations' with those things that they say and do with me, I'm 'very happy' with them.*

*I believe in doctors.*

*My reactions were to do whatever the doctors told me to do because if you don't do what they say, you shouldn't go to the doctors at all. There are two things. Either you do what they tell you when you are ill. When you are ill and I have a problem, I'll go to the psychologist and I'll say, doctor, this is my problem, so and so. One thing I tell you at random and another directly. I suffer. What do I do? You have to tell me and whatever you say, I have to do. If I don't do it, I become embarrassed and I make fun of you. Isn't that how it is? That's what I do, my boy.*

### **Treatment control: Reliance on medical equipment**

#### **Bill**

*That [haemodialysis] is the therapy. Nothing else is suitable because for them to give me kidneys, it's my age now. It doesn't take them. They don't do that now, and even if they did, they're useless. The body would not accept them, because there is no strength.*

*It's very serious but those methods exist, the machines exist, the cleansing exists, and life becomes a bit smoother.*

### **Personal control: Lifestyle behaviour**

#### **Peter**

*Walking, in other words, 'exercise', as they say, whenever you can, the more the better, even two times [a day] is good. To get rid of emotionally whatever harmful*

*and terrible and difficult problems that are present. To get rid of them. To try and think of other things, you start to avoid them, they become avoided, you should try and avoid them.*

*You do those that you can, whatever you can. You can't, you leave it there. There is no nobody's around and he lifts it. If the build is not there, 'finish', stop. If you can't, the heart is the heart! It beats and walks, as far as it endures. You're tired, [then] you rest and you finish.*

*It's good for a person not to eat a lot, to eat healthy [foods], and to stand, in other words, to wander, and work.*

*Health is those basic things, and not only green vegetable food, to eat a variety of everything, and to drink.*

### Anthony

*How do I feel from the beginning until now, I want to tell you, apart from not feeling well from the beginning and I don't feel well now that I have the illness, but I myself have to understand that I have it, I need to monitor them, and that it needs a lot of attention in anything [I do], like I told you before, in anything I eat, in anything I drink.*

*Another says, "I don't have iron in my body" and he says, "Take 'lentil soup', take lettuce, take spinach, take those yellow", what do they call them?, err, they're like squash, something like that, yes, and it is, it is good, good for the sugar, it cuts it for*



*that day, it reduces it, but you can't do that all the time!, You understand what I'm saying? You can't. There are many things that help the 'blood pressure.' You can't eat green vegetables every day. 'Never mind.' Understand?*

### **Personal control: Self-control**

#### Anthony

*Of course, when a person becomes ill, it affects you. You can't say that, "Oh, what's that, it doesn't matter, it'll pass." It doesn't, doesn't pass, so it affects you, it troubles you, but that trouble becomes milder, it becomes more normalised when you know what you have to do, and you follow the rules, the 'regulations' that they say over here, and the 'medication' that the doctor will give you, so that you can become 'established', in other words, in the program that you follow. The only thing you can do. There is nothing else. The effects happen all over the world. A person might affect me by saying a word, I'll forget it, but I cannot forget the illness, therefore you have to do something, isn't that how it is? You have to correct it. If it can't be corrected 'completely', at least keep it, eh, at the 'regular', at the medium level, as they say, 'up and down', so that you know where you stand. Only that.*

*To make life easier, calmer, in other words, so that your mind does not race and you say, "Oh, what will happen tomorrow? It's my last day tomorrow." That thing can't be corrected, that can't be repaired, to worry more, that doesn't happen. You have to bring one problem [around], and say, "Even though I'm ill, even though I think about it, so I won't think about it!", so that you can find a calmness within yourself, peace, understand? like I told you, the worry is the worst of all, there is nothing worse.*

*Not to worry, the worry is the worst of all of them. When you have 'pressure', eh, it's like having an extra illness. In other words, something pressures you, something bothers you, you think about it, you re-think about it, and it makes you become 'more sick.'*

## **Coping Procedures**

### **Use of medical services**

#### Spiro

*I do whatever the doctors tell me to [do]. I don't do anything of my own accord. I do whatever the doctors tell me. I see doctors for my legs, for my arthritis because the dampness is not good because I also have arthritis in the bones, in the 'joints'. I also have [the problem with] my legs where I go to the [hospital] every four 'months'. I usually go to the [hospital]. They 'look after me' and check me for my eyes, my diabetes, my kidney, everything.*

*To the doctor as much as I can so that I can do more things in order to be 'steady' so that I don't sit and think about how ill I am.*

#### Anthony

*I have read it. I have a row of encyclopaedias over there [he points to them nearby] and another two in the 'garage.' I found it from there by myself.*

*I discovered it myself, and I went straight to the doctor. Those are the symptoms. I went on my own and told them what I had*

*I was 'very lucky' that, that I detected it myself. I went to the hospital I told you, the same doctor and I tell him. He tells me, "What do you want?" I told him, "I would like to see a doctor because I'm a sugar diabetic" He says, "Since when!" I said,*

*“‘Since yesterday’, for mercy’s sake!” I said, “What I just told you!” Well, rather than throw me out, they said, “Wait.” They did the first test and they weren’t ‘quite sure’ because it didn’t show that much. It looks like ‘I was feeling much better’ that day. ‘I don’t know what to say.’*

*‘You know what I mean?’, and they told me “‘The next day’”, I told him, “‘The next day’ I’m not coming for ‘another test’, I’ll come so you can keep me inside and fix me up”, and I went “9 o’clock in the morning” with my pyjamas [laughing], with the ‘facilities’ that I had.*

*‘Every three months’, or every six months, I have a cardiologist. I have ‘kidney’, and the other ‘examinations’ for ‘ultrasounds’, etc., etc. in the barrel [MRI scanner], wherever they send me, understand? I am an ‘outward patient all the time’ you know? In other words, they work, I also work with the running, to go with the turns, with all, ‘to make them happy’, understand?*

### Harry

*I don’t care. I take the tablets and wherever it leads. The years are gone, never mind. Better they look after me, it passes here.*

### Michael

*I had to stop the smoking, which I stopped, but to help me, I take oxygen three to four times a day.*

*The oxygen machine. I take oxygen approx half an hour to 40 minutes each time.*

## Bill

*We do what they tell us [to do]. I do the treatment now with the bags, with the machine.*

*It does, it does the provision of the kidneys and, in the morning, it finishes and I start the day as normal again.*

## **Physical activity**

## Spiro

*The diabetes gets worse as the years go by. In particular, I suffer a lot. I exercise to minimize it so I don't lose my sight or my legs. It's a bad illness and so I walk. I've tried until now. I can see and walk well and that's ok.*

## Peter

*[I become] irritated and I walk. I don't think about the irritation on the road. She [wife] better not hear me [said quietly]. I see a beautiful woman on the road, I undress her, in fantasy, and I play games. I come to some thought, okay, therefore, I pass whatever. I surpass it. I bring images, one thing or another, and it passes.*

*You [start to] day-dream, and when you day-dream, then things are okay, you have passed them, they passed, and you know what? You create 'happy' again with yourself. That is the fantasy. It is, in other words, err, impossible, so, you don't need an airplane or anything, understand?*

## **Self-control**

### Bill

*That's why I told you that you can't take more than you are permitted, the usual. If I drink, for example, a coffee in the morning, or I drink a glass of milk, whatever, you have to estimate that, now, for example, I ate a little yoghurt, right, how much water is there in a cup of yoghurt, right?*

*You have to think about those things. You'll eat some 'jelly', for example, how much water has the jelly got inside it, and you have to estimate that the total is one litre, the fluids it has, because if I take on more fluid than that, I'll have trouble.*

### Anthony

*You know, I don't eat meat. I don't eat chicken. I don't eat fish. I like 'pasta, which is the wrong thing. I love pasta. I can have three, four plates of pasta, which is the wrong thing.'*

*That's not allowed. I like to eat 'vegetables, but I can't eat vegetables every day.*

*Today we spent 300 dollars on meat. I don't eat meat', understand?*

*It stopped once for 10 years, 10 or five years, more likely five, without the insulin, 'and I was doing very well!', but I told you, I'm a person who grabs, and I returned back to where I started. In other words, the sugar didn't leave, 'don't get me wrong',*

*the sugar was there, but all was going well 'without the medication! Only with the diet, you know?'*

*But it returned again because I started pinching.*

*I didn't only eat, I drank. I like the drink. 'Oh, I was mad at that time, mad! As I said to you before', when I went and sat at a table, and saw a drink, I saw 'whisky', I saw 'the heavy stuff', not 'wines' or beer, etc, yeah? And 'plenty to eat there. I was going very well', and 'happy drunker', you know. 'No troubles, singing along, being happy. I knew what I was doing. For five years I've done perfect, but the sickness was there!'*

*I fell back again. I fell back, 'yeah.' I returned again to the insulin.*

*Five years, it was 'lovely', I told you, without 'test', without 'medication', without 'insulin.'*

*I held. I was younger. I held. It was actually a big sacrifice, for me. It was a big sacrifice. I didn't even see it [coming]. No. I was going to the 'GP', I had a Greek over here, a friend of mine, it was the son of a friend of mine, and I saw him 'once a month, once [every] three months, you know', err, I was going 'very nice', and he noticed that I was doing something 'wrong', and I returned again to the insulin, 'yeah.'*

*You know what they say?, the way you make your bed, that's the way you sleep on it. I made it that way, I slept there. 'The way you make your bed, that's the way you sleep*

*on it.' That's what happened to me, and since it happened to me, it was a lesson for me again, 'and I carry on, I can stop the insulin tomorrow if I wanted to.'*

*But it's that I want to eat.*

*I want to eat. I want to eat. I want food.*

*I can't have 'both.' I can't have 'both.' I can't have 'both', 'especial' now that I don't walk, I don't move, I don't work. My head goes to the food. I want to open the fridge, to grab what's inside. Many I can't grab, but I grab them anyway. A little, I grab, that's the truth. I can't hide it.*

#### Peter

*You lose the weight, and put it back on again, and, so, the weight has gone to hell, for me. I can't easily 'control' it.*

#### Anthony

*The only thing that I have done, like I told you earlier, when I found out myself that I became ill from the 'sugar' [is that] I tried to repair it. I repaired it to a reasonable extent, and from then until now, I maintain it where necessary.*

*'Some people, they do it three times a day, some people do it twice a day, I used to do it three times a day, and then I cut it to two. Now I cut it to one, my test every morning. I can't be bother because I know the feeling', what I feel in the afternoon, understand?*



Michael

*I try to put the radio on to play music. That's what I do, I don't do anything else.*

*It helps me, the mind forgets.*

*If I think about anything bad in my mind, I put the record on and it plays, and I try and forget that old, the bad that I was remembering initially, with the good from the record that's playing.*

*I had 'businesses.' I sold [them]. I lost my house. I had a house and the bank took it.*

*And I lost everything and all of those come, come to my mind and I try to forget them.*

Anthony

*Eh! It has affected me many times, but as I told you, no matter how much it affects me, because I know what I have, I am careful not to worry so that I don't become more ill, understand?*

*What do I do? The only thing I do is to go and lock myself inside my room. 'Nice.'*

*Quiet. So that nobody can bother me. Allow that moment to pass. I have a 'good break, few times, relaxing, have a glass of water or a cup of coffee and I feel good.'*

*'Whatever it is, whatever bothers me, I will 'relax.'*

*'I have a comfortable sitter inside there in my bedroom. I sit comfortable. I relax. I don't feel [anything]. No, no, I don't feel [anything]. I don't even know if I'm around, and let myself out, forget it, and then five, six minutes later, I feel good. I get up. I have a glass of water. I have a cup of coffee. Especially for this time like this, it's beautiful. I don't know.*

### Harry

*However you look at it, it worries you sometimes but you think about composure at the beginning. Think composure because when you surrender and you worry, you die. You take courage in life. You take courage. That is the best doctor. If you become disappointed, you're finished.*

### Bill

*It affects me psychologically, it affects me psychologically, and slowly, slowly, that serious stress that I have leaves. For example, I might have it for a little while, and then it will leave, because I tell myself nothing can come of it.*

## **Psychosocial Themes**

### **Finding meaning**

#### Bill

*I have that, that stress and say why. I ask myself. "Why, why should this happen to me?" It, it, it, it affects me, this thing. It troubles me a lot.*

*Yes, why should it have started, why should it have started, after all, because I was active once, in my jobs, but now I can't do those things.*

*Alright the kidneys came, right? There is this period that I'll suffer. What will I do? Those [things] that the doctors tell me to do I will do. More than that I won't do, but I can't say, "Oh, what happened to me, oh, why!" That's serious. That's serious, because you become even worse. Just take it psychologically and take one day at a time.*

#### Anthony

*The only thing I thought about when I learnt, discovered it, which I couldn't digest, I couldn't understand, is why it should happen to me? I asked myself that question, why me and not someone else. That's a mistake. I should have taken it like other people take it and say. "It fell to me, it fell to me, I'll fight it, [and] I'll keep it, whatever I can do." I should have done that from the beginning.*

*Why me, yes, I asked myself that question, but when I started to understand it myself, I said, "I have it, I have to fight it." That.*

*It happened. You can't do anything about it. It's like getting a bottle of milk. It spills. You can't gather it and put it back, exactly the same. Isn't it like that?*

*I would have had it 'just the same'. That's written in the books. 'No, no, no, no!' I never explored 'why I came here and got ill, or if I was over there I would be well', 'no, no, no, no, no, no. no!' That was on the cards to happen! It's in the program of each person's life to happen. Its' impossible!*

### Spiro

*How do I view it? I view it as one bad dream. I am yet to believe that it happened to me, but it is a fact, it is 'so'. It happened. What can we do about it now? We don't blame anybody. Do we abuse the people, do we abuse God? Who do we abuse? Our luck? 'Alright.' As long as all the other people are okay, it doesn't matter about us. End of story. Other people are not to blame for my being ill. 'Why' should I be 'jealous' of people who are 'healthy?' 'Alright.' Okay. 'That's my luck', the rest 'alright, happy.' 'Everybody's happy. I have good kids, I have good grandkids', I have made good friends, I have made best men/Godfathers. I have made many [others]. I have made very many things. All this is good.*

### Michael

*A person lays out his plan, how this illness came upon me and did not go elsewhere, and it came to me. That's what I think about, that's what I think about, but I can't do anything about it, it's contagious.*

*Compared to being well and become suddenly ill, from that I submitted to. Indeed that is hard for me to swallow in my life.*

### **Adapting to illness**

### Spiro

*Look. I have accepted that (illness) as inevitable and it doesn't affect me at all now.*

*I have accepted it and nothing affects me. I don't think about it. I don't want to think about it. 'I don't like to think about I'm sick'. Why should I 'think about? Nothing to win.' My aim is to be 'happy.'*

### Peter

*Irreparable, and I get used to it like, like an illness. Whilst you feel pain, whilst you suffer, you take it on board physiologically. You'll say that, "It's one thing to have pain and live with the pain, it's another thing not to have pain." It's the 'damage', in other words, that's occurred.*

*That's it. That's how it is. You took it like as though, in other words, as though they took your hand and you're left with one hand. What can you do? Whatever you can, you'll do. You'll manage. Isn't it like that?*

*It's physiological. Nothing can be done! Nothing can be done!*

Harry

*I don't have, I don't have an illness which is deadly and I've had for years.*

*Nothing has changed. Nothing has changed for me. It continues and nothing concerns me. I take the medication and however far it goes.*

*That's how I am now. Thank God. For the age I'm at, I'm well. The age I'm at now, what do you want me to be?*

Peter

*When that couldn't go in, and they said it can't happen, and I have to have a bypass, it offended because you don't know if you'll remain alive with an operation like that, if the lungs will endure, if everything will endure. Sometimes it happens that three percent of people become dead. If you have some consequences, and other things, in other words, anomalies, sugar and whatever else, well, okay, it happened, after the operation. It offended us because we were operated on from, from 'nowhere', and since we had to be operated on, we ended up accepting that life. In other words, we'll do the required things 'straight', we ate it and we digested it.*

*Well there isn't anything else. 'No way.' How? You'll go and commit suicide? Go, go and fall freely.*

### **Bill**

*Well, it was a little, I took it seriously, but slowly, slowly, I got used to it, I got used to it. What could I do, I can't do anything else, since there is no other, there is no other path. What can I do now? Die, commit suicide? It won't happen.*

*It's the..everyday, each day, 'alright', now, I put on the machine, the night will pass. Tomorrow morning, tomorrow night I'll have the same thing [happen]. That's the everyday which becomes not only a big worry, but it also becomes a routine, it also becomes a routine and you say [that] you accept it.*

*It bothers me, it bothers me, but what can I do? I can't. To do what, what can I do, to eat it and it eat me? It won't happen.*

### **Finding benefits**

#### **Anthony**

*The only thing that I have gained from the time I became ill until now, is that I am still living. That's the biggest 'goal' that I have gotten out of it.*

*Big 'goal! I mean, to live that long, after all this sickness', is a 'goal' for me, great 'goal, better than anything!'*

*Life is sweet.*

*'Better, better quality of life. A lot better. We don't miss anything'. We have everything. 'Even if we got a sickness, we declare' we have everything. We lack nothing, and we are not embarrassed to invite a person to our home and tell him, "Sit and eat", whereas many people over there don't have enough to eat, even now!*

Spiro

*"In all this life, apart from the health, thank God", I said, "I'm fine."*

Bill

*Life now is a bit serious as a result of the illness, but still we get by. We're progressing well.*

## **Finding a purpose**

Anthony

*As much as you say that your ill, that you want to leave, you want to do, you want to show, there arrives a moment that you say, "Why?, I have to live", and when you believe it, that thing happens. When you don't believe it 'on your mind', it doesn't happen at all.*

*You lose everything! So you have to be faithful in what you're thinking, in what you say,..and you'll say it again, that "I have to live, to see those children grow up, to see them 'perhaps one day to get married'", understand? "Even if I can't walk, to go to*



*the church, to see them 'happy.' ” The 'new generation', understand? I have, my nephew who is in the 'third year university' now, from my son. Wwhat is his title he learnt? He has, anyway, I'll remember it. He's 'twenty years of age now, six feet three' [laughs quietly]. 'A giant', understand?, and I'm only five feet seven.' He has some hands like that, his hands. He gives me life to wait, to see him get married, to get. Next year, he's finishing. To get what he'll get, his diploma, economist, yes, and I would like to see him get married, to be 'happy', marry a woman. My niece, his sister, is 11. I also want to see her [get married], those are from my daughter, the children I'm talking about, understand? 'Well', those will make me 'happy.'*

*To think about the good, not the bad.*

### Spiro

*You have to view life from the positive side. We are here for a limited time. We are not here forever. 'Nobody lives forever.' Am I right? 'History.' If you take 'history, years, years, years, years', so many people passed through. What did they do? For example, say you made 10 million dollars and you died. You don't take anything with you.*

*Therefore, the aim is to be good with the people you live with, with your family, with your children, your friends. That's how it is. To not worry about other things.*

### Peter

*At the beginning it's that the illness cuts you. At the beginning before the, the operation, the illness cuts you in energy and in action and you think. "How many more years will I live?" You think that, "How many years, I wonder, I'll live, five, 10, three, two?", and that 'how' you keep inside. It doesn't stop. Every time you go to do*

*something, [you say], “What do I want to do [with that], to write a book, will I have enough time?” Afterwards, you see others write them and you say, “What happened?”, and say, “Why don’t you look at living well, with the final day, with the final moment, and live each moment well!” That is the connection.*

### Michael

*Many times I decided to end my life. I took tablets to commit suicide.*

*My life was good before I became ill. After I became ill, my life was finished.*

*I feel like a finished person, like a finished person.*

*I don’t have a good mood.*

*For anything.*

*How do I see it, like a finished person. There is no cure for me. There is no life.*

### **The role of support: Medical and social**

#### Harry

*What can the people do. The illness is [for] the doctors. The best men, what can they do for you?*

*For the illness, I have my own support. What can the people do for me? What can the support do for you? What the support will do for you?*

*I have support, in other words, support which if you have something, my best man calls me, friend, whoever else, to help you, then they help you, and those people, what can they do for you? What can they do for you? Now that I'm alone, if I'm not well, I call and some friend comes and we sit, let's say.*

*You welcome people. [For] the illness, there is the doctor, the medication, and that. You call your brother, what can he do, what can he help you with? Apart from a visit, what else do you want him to do? To examine you, what can he do?*

*Well, in a consoling way, you say, we converse, like that. They can't do anything else for you.*

### Spiro

*I don't have any expectations from my friends because each person has their own home. He can't leave his own home. You and I are friends, us two. I am 'crook' for one week and I need your help. Are you going to leave your home, your family, your children to come and look after me? I'll go to the hospital, I'll stay there, and the nurses and doctors will look after me. I don't want an expectation of my friend, or my brother, or my sister to look after me. That's why there are hospitals, so that they can look after me.*

*My wife has helped me, my children have supported me. I also have many friends that have helped me. Everything else is ok. Thank God. I don't have any complaint.*

Anthony

*It's a wonderful thing to provide someone, either in verbal, or written form, or with medication, or with whatever idea, an ill person. The whole thing is to take it within you, and think that that person, whether he provides me with medication, or whether he provides me with a good conversation, he wants to help me, in which case, it is good for me to listen to him, don't you think so? In other words, I don't want money! I want a good conversation!, I want a 'practical medication', if he has it, as there are many which help the sugar, understand?*

Spiro

*I never had any problem with money. I had no expectations, I didn't want to say, hey, [interviewer], give me 100 dollars and 500 dollars to get by. It's more about if you happen to come by my house and talk and eat with me, tell me how you're going, that's the support. What else?*

Anthony

*Even if I don't have social support, <interviewer>, it is of course a beautiful thing to have if you can, but the bottom line is that nobody can offer me more than what my home can offer me, first and foremost my home, nobody else can offer me, they told me about offering me, the 'community.'*

*'I've done the rehab for six months.' They 'offered' to fix my bathroom, with 'handles', my floors, but I had already fixed them. 'I spent 300,000 dollars here already, to do that. I got 3 bathrooms, I got 3 toilets, and I got everything close to me.' I don't need anything for them to bring me. They talked to me about bringing a nurse to bathe me, all of that. I said, "No", my wife will do it for me. I said, "Give her somewhere else where she is needed more than on me", understand? 'I wouldn't accept it, I wouldn't accept it, no, no, they offered me, no, no, no', but 'I wouldn't accept it. Even they offered to take me once a day for a cup of coffee, a special driver, to take me for a shopping or something', I told her, "No, I have my wife so many years. I have made her an 'expert' behind the wheel. She will do everything for me, nobody else. If my wife's not here, I have my children. They come once a week. Somebody will take me."*

*'I wouldn't accept it' because somebody else needs it more than me, 'not because I'm a proud of myself', no, no, 'no, no, no, no'. I'm nothing, I'm nothing, I love to be a normal man, but I like to accept exactly others they need them more than me! That's the situation, understand? "No", I told them that for the moment. In the beginning I say, "Yes", and then I ring him up and told him, "Look, is not right, is wrong. What I told you is wrong. I never thought twice. Please, I want you to give the service to someone who needs it more than me", understand? 'No, no, no, no. I got nothing to. No, no, no. I prefer to be independent.'*

### Peter

*Now it offends us when a person runs and gives a lot of support, because it shows you that you are unfortunate, and I avoid, avoid it and don't want a lot of it. One thing*

*that I have to do, and it needs me to, to, how do we say, make a decision.*

*Furthermore, I am not to be served upon by others.*

*To tell you the truth, I didn't like it. Recognition, yes, but not support. The support, you know what? It's like being a special, different, person, the patient, and you're supported [by], you know, the community, everyone, it gives you a, b, c, whatever.*

*No!, I am equal. Recognition, yes, for what I have, sympathy, yes, but support, nothing. Now look, the government provides support because "Athens" doesn't give the pension. What other support to get? If you can't manage with something, if they give you a license, 'parking', and, I don't know, whatever, okay, but since I can, since I can drive, I can do, in other words, it's not required! When someone comes and says, "Take this", I'll take it and continue with it when I cannot. Since I'm able to and I have, it's not required, it's not required. You might say, "Does it harm anyone?" It doesn't harm, well, why, since, look, to some extent, it affects my nerves a little, supports, things which show that you have, you suffer from something and you need support, it shows that you are not healthy, you are ill. I feel good.*

*Since I do everything, whatever I need, I do myself, I don't ask from anyone, I don't ask from anyone, a walk, food, whatever, what else is there?*

### Anthony

*A great deal, a great deal, from my lot, and a great deal from my doctor, who looked after me with big, in other words, sincerity, who looked after me from the beginning until now, and they are still looking after me, of course, as a patient, which I am, so many years. He has to 'look after it', that's the truth, yes.*

Michael

*Only the doctors, what support? Nothing else.*

*I don't have relatives, nobody.*

*At the beginning it was difficult, afterwards it became easier.*

Bill

*The social support is not a bad thing, but the social support will come from your family, because your friend, relative, cousin, will tell you, he'll come one day to ask how you are, how you're going, whatever. He'll leave. Your family will be near you and they'll look after you, support you, [and] help you as much as you want, that's it.*

*You can say your problems to your partner, your wife, or your wife to her husband, and together we try and solve them. We can't leave them as they came.*

Spiro

*You don't feel well. You don't feel well whenever you are ill. In other words, those who are well cannot understand how bad it is for the ill people. There is nobody who knows. However, frequently, they tap you on the back and afterwards they stand up and leave at 5:30 and tell you goodbye. If you suffer and feel pain and are ill, only you know your own pain. Nobody else can take your pain.*

### Anthony

*The only thing that I have used, like I told you in the other questions, is that I myself am strong, so that I can come out from the situations.*

*From within me, yes. Only, only that, only me! Nobody else, because even if someone wanted to help me, he can't help me! To tell me something I don't know? I know it all. It's not one year, it's 33 years! Understand?*

### **The importance of social interaction**

### Bill

*'Oh' it's a beautiful thing, a very beautiful thing, to have contact with people, to say a joke, to talk about your pain, they also tell you. To talk about your pain and for them to understand you, like I want someone else to tell me his pain, I'll understand him. I'll feel it, if I can help him, I will, if I can't, I can't. 'Sorry.' But it's a big deal that, for a person to have contact with another person, a very big deal, because after having gone through these illnesses with my wife together, our friends have always been near us, they're near us, which gives you a big relief, it gives you a lot of happiness, you forget your pain. A friend, relative, whoever comes, he has a good conversation with you, and that is valued and gives you courage in life.*

### Spiro

*What I see is that when I'm ill and don't see anyone, I go crazy, 'go crazy.' I didn't want that to happen to me, and despite this, I'm doing rather well. I 'enjoy' myself. I*



*say let's go for an outing to Sorrento, and we go. I get the car and we go. We go there and walk on the beach and see jogging.*

Peter

*Well, I can't say anything now. I don't have social interaction now. You know what? I'm 72 now and I stopped the interaction because of the influence, and now I am, I look to pass my time well, nicely, calmly, and can I tell you something? From the time I did the operation, a weight lifted off my shoulders. I left the conversations. I left the seriousness.*

Michael

*I don't want to go to a lot of bother. I don't want to go to many visits. I want to always be 'alone', on my own.*

*Well, it's difficult for me, now that they bring me to a circle with many people around me. I want my solitude and peace, nothing else.*

*I feel uncomfortable. I don't want fuss. I don't want noise and other. I want to be on my own. Quiet.*