



# A QUALITATIVE INVESTIGATION OF THE EXPERIENCES, PERCEPTIONS AND UNDERSTANDINGS OF PEOPLE WITH A CHRONIC CONDITION

MAY 2002



The Queen Elizabeth



**A QUALITATIVE INVESTIGATION  
OF THE EXPERIENCES, PERCEPTIONS  
AND UNDERSTANDINGS OF  
PEOPLE WITH A CHRONIC CONDITION**

**MAY 2002**

**Julianne Cheek**

**Candice Oster**

Centre for Research into Nursing and Health Care  
University of South Australia

*in conjunction with*

Centre for Population Studies in Epidemiology  
Department of Human Services, South Australia

This work is copyright. It may be reproduced and the authors welcome requests for permission to reproduce in whole or in part for work, study or training purposes subject to the inclusion of an acknowledgment of the source and no commercial use or sale. The authors will only accept responsibility for data analyses conducted by the study staff or under the study staff supervision.

Published May 2002 by the South Australian Department of Human Services  
PO Box 287, Rundle Mall  
Adelaide 5000  
South Australia, Australia.

*National Library of Australia Cataloguing-in-Publication:*

Cheek, Julianne, 1957-.

A qualitative investigation of the experiences, perceptions  
and understandings of people with a chronic condition.

Bibliography.

ISBN 0 7308 9193 3.

1. Chronically ill - South Australia - Adelaide - Attitudes. 2. Patients - South Australia - Adelaide - Attitudes. 3. Chronically ill - Care. 4. Health surveys - South Australia - Adelaide.  
I. Oster, Candice. II. University of Adelaide. Dept. of Medicine. III. University of South Australia. Centre for Research into Nursing and Health Care. IV. Centre for Population Studies in Epidemiology (S. Aust.). V. Title. VI. Title : North West Adelaide health study.

616.0440994231

Further copies of this publication may be purchased from the Centre for Population Studies in Epidemiology (CPSE) or may be downloaded from the CPSE web site: <a href="http://www.health.sa.gov.au/pehs/cpse.html">http://www.health.sa.gov.au/pehs/cpse.html</a>
-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

# TABLE OF CONTENTS

<b>EXECUTIVE SUMMARY .....</b>	<b>9</b>
<b>Participants and methods .....</b>	<b>11</b>
<b>Results .....</b>	<b>12</b>
<b>Discussion .....</b>	<b>16</b>
<b>CHAPTER 1: BACKGROUND AND AIMS OF THE STUDY.....</b>	<b>19</b>
<b>1.1 North West Adelaide Health Study.....</b>	<b>20</b>
<b>1.2 Situating the study in terms of the literature .....</b>	<b>21</b>
<i>1.2.1 The experience of chronic conditions .....</i>	<i>21</i>
<i>1.2.2 Managing chronic conditions .....</i>	<i>24</i>
<i>1.2.3 Chronic conditions and risk.....</i>	<i>27</i>
<i>1.2.4 The present study .....</i>	<i>29</i>
<b>1.3 Aims of the study .....</b>	<b>29</b>
<b>CHAPTER 2: METHODOLOGY .....</b>	<b>31</b>
<b>2.1 Methodology.....</b>	<b>32</b>
<i>2.1.1 Ethical considerations .....</i>	<i>32</i>
<i>2.1.2 Sample.....</i>	<i>33</i>
<i>2.1.3 Demographics of the sample.....</i>	<i>33</i>
<i>2.1.4 Data collection: the in-depth interview .....</i>	<i>33</i>
<i>2.1.5 Data analysis .....</i>	<i>34</i>
<b>CHAPTER 3: FINDINGS.....</b>	<b>35</b>
<b>3.1 Initial diagnosis .....</b>	<b>36</b>
<i>3.1.1 The diagnosis .....</i>	<i>36</i>
<i>3.1.2 Thoughts and feelings at initial diagnosis .....</i>	<i>37</i>
<b>3.2 Living with a chronic condition .....</b>	<b>38</b>
<i>3.2.1 It's "always in the back of your mind" .....</i>	<i>39</i>
<b>3.3 Managing a chronic condition .....</b>	<b>43</b>

3.3.1 “They only ask what’s wrong”: the need for health professionals to have the whole picture.....	44
3.3.2 Managing one’s self.....	48
<b>3.4 Risk.....</b>	<b>50</b>
3.4.1 “... it’s a bit of a balance” .....	50
<b>CHAPTER 4: DISCUSSION.....</b>	<b>57</b>
<b>4.1 The need to understand the individuality of the experience of chronic conditions .</b>	<b>58</b>
<b>4.2 Implications for health care professionals.....</b>	<b>60</b>
4.2.1 Diagnosis of chronic conditions .....	60
4.2.2 Management of chronic conditions.....	62
<b>4.3 Multi-dimensional health research.....</b>	<b>65</b>
<b>APPENDICES .....</b>	<b>71</b>

## *Acknowledgments*

This project was conducted by the Centre for Research into Nursing and Health Care (University of South Australia) and formed part of the North West Adelaide Health Study. We would like to acknowledge the contributions of:

- Participants of the North West Adelaide Health Study who gave up their time and shared their experiences, perceptions and understandings of living with a chronic condition.
- The other chief investigators of the North West Adelaide Health Study, namely Professor Richard Ruffin, Dr Patrick Phillips, and Associate Professor David Wilson.
- Members of the North West Adelaide Health Study research team, including Anne Taylor, Catherine Chittleborough and the clinic staff.

Many thanks to all of you,

### ***Research Team***

Professor Julianne Cheek

Candice Oster

November 2000





# **EXECUTIVE SUMMARY**

The study reported here is part of the North West Adelaide Health Study, an epidemiological population-based cohort study exploring chronic conditions in the north west region of Adelaide, South Australia. The north west region of metropolitan Adelaide is a priority area because of the greater than average health burden in chronic conditions (South Australian Health Commission 1990). This, combined with its lower than average socio-economic status, makes the region a target for strategies to improve population health.

The North West Adelaide Health Study comprises both qualitative and quantitative components. The quantitative components involve the use of biomedical measures to ascertain disease prevalence as well as administration of health related questionnaires, including a quality of life questionnaire, a questionnaire on health-related behaviours, and questions addressing specific issues relating to asthma and diabetes. The qualitative component of the study comprises an exploration of people's experiences, perceptions and understandings of what it is like to live with and manage a chronic condition. It is this qualitative component that forms the focus of this report.

The importance of exploring the perspectives and views of the patient is being increasingly recognised internationally in research into chronic conditions (Kaufman 1988; McWilliam et al 1996; Skilbeck et al 1998). The Australian National Diabetes Strategy and Implementation Plan (Colagiuri et al 1998) likewise emphasises the need to explore the patient's perspective in order to better inform strategies for dealing with diabetes. Existing qualitative research into the ways in which chronic conditions are experienced show some similarities in their findings across conditions, countries, participants and qualitative approaches (Kaufman 1988; Cleaver 1994; Forbes 1999). This body of research demonstrates the possibility of a pattern of the experience of chronic conditions. This pattern can be conceptualised as ranging from the appearance of the first symptoms, through the impact of diagnosis, to the ongoing development of a 'self' that incorporates the condition. Paradoxically, however, within this apparent pattern there is also a sense of the individuality of the experience.

Providing patient education and information is a common strategy for the management of chronic conditions such as asthma and diabetes. However, knowledge of what should be done is not necessarily followed by actions on the part of those with the condition. In the qualitative research literature on the management of chronic conditions, it is increasingly recognised that adherence with health schedules in particular is determined in part by the patient's individual perception of the condition and its management (Patton 1990; Hjelm et al 1999; Leyshon 1999).

Overall, the literature on the management of chronic conditions suggests a more individual and less global approach to assisting people to manage their condition. Part of this approach involves understanding people's perceptions of the risks associated with their condition, and what they do as a consequence of those perceptions.

The small-scale exploratory study reported here continues the emerging research tradition of qualitatively exploring the ways in which people understand various aspects of chronic conditions, including living with a chronic condition and perceptions of management and risk.

## **Participants and methods**

The study aimed to qualitatively explore participants' experiences, perceptions and understandings of what it is like to live with and manage a chronic condition. The study was exploratory and interpretive in nature. A small sample of people who took part in the biomedical part of the North West Adelaide Health Study participated in in-depth interviews.

### **Sampling and sample size**

Purposive sampling techniques were used in order to ensure information-richness. Information rich cases are "those from which one can learn a great deal about issues of central importance to the purpose of the research" (Patton 1990). Ten participants from the North West Adelaide Health Study who attended the clinic and had a diagnosis of asthma or diabetes confirmed by a doctor took part in the interviews. Five were diagnosed with asthma, and five were diagnosed with diabetes. There were two males and three females with diabetes, and two males and three females with asthma. The participants ranged in age from 19 to 83 years.

### **Data collection**

Face-to-face in-depth interviews, averaging 1½ hours each, were conducted to explore the experiences, perceptions and understandings of living with a chronic condition. The interviews were semi-structured around an interview schedule where participants were encouraged to talk about the following: their experience of diagnosis; their perceptions and understandings of their current health status; the meaning of having the condition to the participant's life; their experiences, perceptions and

understandings of management issues; their perception of risk in relation to the condition; and the role of health professionals in the management of their condition. The interviews were audiotaped and transcribed.

### **Analysis of data**

The research team independently reviewed each transcript. The analysis broadly followed the four stages identified by Ekman and Segesten (1995):

- the entire material collected was studied to give a sense of the whole;
- themes and categories were identified;
- recurrent patterns were identified;
- summative themes and research findings were developed.

The reviews were exchanged and any disagreements were discussed and resolved by consensus. Themes and issues across interviews were generated and these were then progressively grouped into categories of similar themes. Major categories of themes or issues were produced as a result of the analytic process.

### **Research Ethics**

Ethical approval was sought and granted through the relevant ethics committees.

## **Results**

Four major clusters of themes were identified. These clusters were: the experience of initial diagnosis, living with a chronic condition, managing a chronic condition and perceptions of risks relating to the condition. These are discussed below.

### **The experience of initial diagnosis**

When asked about their experience of the initial diagnosis, participants related a range of thoughts and feelings. These included shock, feelings of being unable to escape from the condition, concerns about how they would be affected, denial, pain, fear of dying, uncertainty, and in some instances the confirmation of an expected diagnosis.

### **Living with a chronic condition**

The overriding theme to emerge from participants' views about their thoughts and feelings of living with a chronic condition was that the condition is something that is

“always in the back of one’s mind.” Aspects of the condition always being in the back of one’s mind included:

*The experience of living with the condition as an ongoing battle*

Living with the condition was experienced as a battle once there was acknowledgment that the chronic condition did exist and that the person had it. However, there was also a battle on some participants’ part before that, a battle relating to getting to the point where they could actually accept that they did have the condition.

*The condition as an ever present burden*

There was the sense of the chronic condition as being a burden that was always present in terms of it removing pleasure from participants’ lives, leaving them feeling out of control, and requiring particular activities to be done or avoided.

*The sense of not being normal*

Participants experienced the feeling of not being normal in terms of being aware that they were different from other people. Further, they were uncertain as to how to describe themselves, or what part of the condition was of ‘themselves’.

*The experience of “niggly” things*

Participants talked about the “niggly” things, or the everyday mundane minutiae that were always in the back of their mind, that constantly reminded them of the fact that they were having to manage a chronic condition.

*Just going along with it*

Participants spoke of the need to “go along with it” in the sense of needing to acknowledge that they have the condition. Participants also spoke of the need of having to accept that the condition was going to be an ongoing part of their life.

*Dealing with others*

Participants identified that there were two sorts of “others” that needed to be dealt with. There were those “others” who were also diagnosed with the chronic condition, and those “others” without it. Participants spoke of being able to identify with those who had the chronic condition, and of receiving empathy and support from them. On the other hand, participants did not necessarily find it easy dealing with others, including health professionals, who did not have the same chronic condition.

## Managing a chronic condition

Two areas relating to the management of chronic conditions emerged: participants' experiences in relation to the interactions that they have had with health professionals, and their experiences of the self-management of their condition.

With respect to participants' experiences in relation to interactions with health professionals, it was important that health professionals had what participants termed "the whole picture". Gaining the whole picture involved the following elements:

*The need for good information and communication skills to both convey and explain the information given*

Participants preferred health professionals to be easy to talk to, and to indicate that they want to listen. Further, when explanations were given they needed to be at the appropriate level. Participants required large amounts of information relating to the condition and its management. Some participants referred to the fact that they felt like the health professional assumed that they (the health professional) knew everything, and that the participant did not know very much. Many participants spoke of the fact that they would weigh up how credible the health professional's information was, as opposed to their own experience.

*Having time*

An important part of health professionals' having the whole picture was the health professional actually having time to get the whole picture. Participants spoke of the fact that some health professionals had little patience, and certainly didn't seem to have any time for detailed discussion.

*Being interested in "me"*

Participants discussed the need for a health professional to be interested in "me", the person with the condition, not just the condition itself. Participants wanted health professionals to ask why things were happening, why people were behaving in the way they were, or why they weren't managing.

With respect to self-management which was the second area identified as related to the management of chronic conditions, most of the participants' responses could be distilled into the notion of ownership of the condition. Related to this notion of ownership were three themes:

*Taking/accepting individual responsibility for the management of the condition*

All participants spoke of the fact that they themselves needed to cope with the changes that had been enforced upon them, that they had to adapt their lives, and that they had to accept that they actually had the condition. They spoke of the need for self-surveillance, accepting responsibility for that surveillance and then managing the condition appropriately.

*Management as very personal and individual*

When it comes to the management of chronic conditions, participants were aware of the fact that everyone is different, and emphasised the importance of being aware of these differences. Participants spoke of needing to learn how to deal with their own condition themselves.

*Being in control*

This notion of “being in control” was articulated by participants in terms of taking control of the ongoing management of their condition, and actively making decisions such as when to seek help. Many participants felt that learning how to manage their condition involved learning what to do, and knowing if it worked by how it feels.

**Risk perception**

A central theme relating to participants’ perceptions of the notion of risks associated with their condition was that risk was viewed as being “a bit of a balance”. Three contributory themes relate to risk as being “a bit of a balance”:

*Doing the wrong thing*

Risk was often defined by the participants as “doing the wrong thing”. For example, participants spoke of the actions that they equated with taking risks as cheating. Others just said that despite the fact that they know they shouldn’t be doing what they are doing; they “do the wrong thing” anyway. Some participants were quite aggressive in terms of the fact that yes, they were doing the wrong thing, and “that’s okay by them”. Participants spoke of the need for self-control, the notion of “knuckling down”. This involved participants deciding for themselves what they were prepared to “knuckle down” and do.

*Weighing up*

Weighing up was discussed in terms of “minimising risk versus minimising lifestyle”. At the core of this was a sense from participants that even if they took all precautions,

there was no guarantee that they would not have an asthma attack or develop a problem from their diabetes. There was, however, a guarantee that they weren't going to, in their words, "live their life". Consequently, in most cases a conscious decision was made by participants in terms of whether or not to take what health professionals term a 'risk'.

#### *The immediacy of a risk*

Risk was perceived by some individuals in terms of whether the risk seemed real or serious at this particular moment in time. For some participants the risks do seem real, and they will therefore take appropriate actions to eliminate or minimise risk. For others though, they felt that the risk was not high enough, or the outcome of the risk was not negative enough, to warrant doing anything about it. For these participants there had to be an immediate tangible risk, such as for example, "being told they would die tomorrow unless they gave up smoking."

## **Discussion**

Although the findings of a small scale study such as this may not be generalisable, implications do emerge for the practice of health care professionals. They are now discussed in terms of both the diagnosis and the ongoing management of chronic conditions. Such findings also provide the basis for further research, which will form part of the ongoing North West Adelaide Health Study.

## **Diagnosis**

Two important areas in the diagnosis of chronic conditions that need to be attended to by health professionals are support and information. These are discussed below.

#### *Support*

It is important that individuals being diagnosed with chronic conditions are given individually tailored support at this time, and that they are reassured that the range of thoughts and feelings being experienced by them are those experienced by many people. The study highlights the possibility for "others" with the particular chronic condition to be more involved in supporting individuals who are newly diagnosed and learning to live with the condition in an ongoing manner. This may make it easier for some individuals to accept the fact that the condition is real, and that the diagnosis will mean changes in outlook and lifestyle.

### *Information*

In light of participants' responses pertaining to the provision of information, health professionals may need to tailor the information provided for the individual at diagnosis and beyond in terms of their individual needs and level of understanding of the condition. Further, there may be a need to provide more targeted information and education for significant "others", such as family members, work colleagues and so forth. This provision of information would need to be done in conjunction with the patient.

### **Ongoing management of chronic conditions**

Traditionally, management schedules for conditions such as diabetes and asthma have been developed on a generalised rather than an individual level, leaving the individual and his or her experiences, perceptions and understandings out of the equation. The significant rates of so-called "non-compliance" with health schedules suggests that this management strategy is not effective. Participants' discussion of issues of management and risk perception highlight the problems associated with assuming that everyone who is diagnosed with a particular chronic condition is necessarily the same. In the following sections, possible strategies for a more effective approach to ongoing management are discussed.

### *Negotiation*

The notion of partnership and negotiation has emerged from this study as being at the heart of the successful management of a chronic condition, by both the patient and the health professional. The study findings support the position that negotiation in the development of health schedules and management plans is crucial.

### *Taking the context into account*

It is also clear that it is necessary to consider the whole person in their entire context in order to work with them in developing a management program. Contextual factors include significant others, the person's work place, the social context in which they live, lifestyle choices and individual priorities. Participants in the study were consciously weighing up managing the condition with its impact on their lives and making choices accordingly.

### *Communication*

Communication needs to be a two-way process, with the health professional needing to take into account contextual factors and other forms of information that may be

accessed by the person seeking treatment, as well as the person themselves attending to the information presented to them by the health professional

*Managing risk perception* - The analysis relating to participants' perceptions of risk provides an insight into the conscious decision making or weighing up process by people with chronic conditions. In addition the study found that differences in the perception of the outcome of risk related to perceptions of the immediacy of that risk. Thus if the risk seemed to be too far in the future it was less likely to be of concern or seem real to the participants. These findings demonstrate again the need for health professionals to work closely with the understandings individuals have about their condition, about 'compliance' and about risks associated with the condition. This includes making the risk seem real to the person concerned even if it does not seem immediate.

### **Multi-dimensional health research**

Finally in a different vein, our findings illustrate the importance of a multi-dimensional approach to understanding chronic conditions and their management. Fenton and Charsley (2000) argue that by mixing dimensions of analysis it is possible to refine and to complement purely quantitative approaches such as epidemiology. The results of the present study will be incorporated into the epidemiological population-based cohort design in order to refine and improve the methods of data collection employed and the assumptions therein. As such this multi-dimensional and multi-method study will better mirror the reality of those with a chronic condition.

# **CHAPTER 1: BACKGROUND AND AIMS OF THE STUDY**

This study formed one qualitative part of an epidemiological population-based cohort study of major priority issues relating to chronic conditions in the north west region of Adelaide, South Australia. Throughout this report we will use the term ‘chronic condition’ rather than ‘chronic disease’ or ‘chronic illness’ to describe asthma and diabetes. This is in order to avoid the more negative connotations of the terms ‘disease’ and ‘illness’. We recognise however that the various ways of describing these conditions are not neutral terms; rather they are all loaded with connotations and effects. This is demonstrated by the difficulty of the study participants themselves to decide which is the ‘correct’ terminology.

### **1.1 North West Adelaide Health Study**

The North West Adelaide Health Study is an epidemiological population-based cohort study exploring chronic conditions, including asthma, diabetes, mental health and quality of life in the north west region of Adelaide, South Australia. The north west region of metropolitan Adelaide is a priority area in health care management because of the greater than average health burden in chronic conditions (South Australian Health Commission 1990). This, combined with its lower than average socioeconomic status, makes the region a target for strategies to improve population health. The North West Adelaide Health Study comprised both qualitative and quantitative components. The quantitative components involved the use of biomedical measures to ascertain disease prevalence as well as administration of health related questionnaires, including a quality of life questionnaire, a questionnaire on health-related behaviours, and questions addressing specific issues relating to asthma and diabetes. The qualitative component of the study comprised an exploration of people’s experiences, perceptions and understandings of what it is like to live with and manage a chronic condition. Individual interviews were conducted with participants from the North West Adelaide Health Study who had a confirmed diagnosis of diabetes or asthma.

In order to provide a context for the report to follow we begin by reviewing the qualitative research that has been conducted to date in the area of chronic conditions, in terms of both the experience and the management of these conditions.

## 1.2 Situating the study in terms of the literature

### 1.2.1 The experience of chronic conditions

The importance of exploring the perspectives and views of the consumer/patient<sup>a</sup> is being increasingly recognised internationally in research into chronic conditions (Charmaz 1987; Kaufman 1988; McWilliam, Stewart et al 1996; Skilbeck, Mott et al 1998). The Australian National Diabetes Strategy and Implementation Plan (Colagiuri S, Colagiuri R & Ward J et al 1998) likewise emphasizes the need to explore the patient/consumer's perspective in order to better inform strategies for dealing with diabetes. The plan states that its vision is to develop a system of diabetes prevention and care in the future which is:

“underpinned by comprehensive and co-ordinated research programs which systematically identify and address deficits in knowledge about all aspects of diabetes prevention and care and which seek and reflect consumer perspectives.” (p4)

In order to understand a person's experience of a chronic condition, particularly in terms of the impact of diagnosis and managing the condition, it is vital to explore the meanings the persons themselves attribute to their condition. Without this information, health care professionals are limited in their ability to provide people with assistance with the management of chronic conditions in a way that reflects the person's articulated needs and understandings. Qualitative analysis is an appropriate approach to explore such needs and understandings as it is useful in studying meanings, as well as:

“why people act in particular ways and in investigating the relationship of beliefs and behaviour to one another. It is the research technique of choice in studying how ethnic, religious, or social variables influence health, disease, illness, and help-seeking behaviour” (Helman 1991, p120).

Qualitative research into the ways in which chronic conditions are experienced show some similarities in their findings across conditions, countries, participants and qualitative approaches. This is particularly the case in research that outlines the

---

<sup>a</sup> The terms 'consumer', 'patient' and 'subject' are used interchangeably throughout the literature review, depending on the terms used by the authors of the articles concerned. In our study we prefer to use the term 'participant' to avoid the implications that people are passive recipients of health care and to emphasise their role as participants in our research.

various aspects of the lives of people who live with a chronic condition. While the findings of this corpus of research are not identical, there are considerable similarities. Cleaver and Pallourios (1994) conducted a phenomenological study into the experience of adult insulin dependent diabetics in South Africa. Based on the results of the study, they suggest that the 'essence' of being a diabetic includes:

- a retrospective perception of a relatively carefree life before the diagnosis;
- the appearance of the first symptoms and their consequences;
- the impact that the diagnosis had on the awareness of the subjects: this includes relief, shock, fear, loneliness and confusion;
- an emerging pattern of the life-world of the subjects, which includes conflict related to the body, loss of freedom, mood swings, irritability, changes in social relationships and control;
- fear of the future (Cleaver & Pallourios 1994, p180).

Phenomenological analysis was utilised in a further two studies of the experience of chronic conditions. Forbes (1999) conducted a comparison study using two qualitative methods (phenomenology and concept mapping) to explore the notion of hope in older adults with chronic conditions in America. She noted a close correspondence between the themes generated in the phenomenological study and the statements generated in the concept mapping study, although the phenomenological analysis provided greater descriptive detail. The phenomenological themes included: initial awareness of the condition, seeking help, personal hardships, challenges to hope, connections, coping with the situation, taking back control, and losing, maintaining and regaining hope. The concept mapping clusters included: difficulties, unproductive attitudes and behaviours, hitting bottom/hopelessness, sorting things out, protecting yourself, facing reality, changing attitudes, and transcending. In another American phenomenological study, Kaufman (1988) explored the experiences of people who have experienced stroke, and noted two themes, namely confronting physical limits and managing intimate relationships. Even in research that is ostensibly exploring a phenomenon other than the experience of chronic conditions, similar patterns have been noted. For example, in a study exploring the ways in which older people with chronic conditions experience health and health promotion, McWilliam et al (1996) note that "patterns of health and health promotion have many similarities to patterns of living with chronic illness" (p10).

The findings of the research studies outlined above demonstrate the possibility of a pattern of the experience of chronic conditions. This pattern can be conceptualised as ranging from the appearance of the first symptoms, through the impact of diagnosis to

the ongoing development of a 'self' that incorporates the condition. While the notion of a pattern of the experience of chronic conditions is supported by the literature, within this apparent pattern there is also a sense of the individuality of the experience. This individuality of experience is implicitly acknowledged in the research outlined above, particularly through the use of quotations from interview extracts. The individuality of the experience of a chronic condition can be seen more explicitly in the research into the concept of 'self' in chronic conditions and the notion of transformation.

The concept of 'self' is an important one for people who have been diagnosed with chronic conditions, and qualitative approaches have been used to explore this concept in people with various conditions. For example, in a case study exploration of the ways in which people with chronic conditions develop a narrative self in autobiographical accounts of illness, Kelly and Dickinson (1997) discuss the ways in which the participants "interweave their lives with the experience of illness" (p273). In another example, Charmaz (1987) looked at the ways in which people with chronic conditions handle identity problems in their struggle for a self. A related issue in the experience of chronic conditions is the concept of transformational experiences. Transformational experiences are said to result in a transformation from one way of 'being' to another, involving restructuring of both the illness experience and of the 'self'. Paterson, Thorne, Crawford and Tarko (1999) conducted a qualitative study using a grounded theory approach to explore the experience of transformation in a sample of 22 adults with Type 1 diabetes who were successful in their self-care management. Paterson et al (1999) noted that participants "described transformation as a dynamic evolution" (p791), which the authors used to define a model of transformation based on the experiences of the participants. This model involved a dynamic process where challenges, through either a threat to self-integrity or challenges presented by others, lead to transformational experiences. Transformation also resulted from the "differentiation of the self from the body", which entailed "believing and acting as if the individual was the primary agent of the outcome of the challenge process, perceiving the self as the subject and no longer the object of the disease" (Paterson et al 1999, p795).

The notion of the individuality of the experience of chronic conditions can be seen in the transformational experience. For example, Paterson et al (1999) noted that participants demonstrated a variety of personal styles in the experience of transformation. Related to this notion of the individuality of the experience of chronic

conditions, participants viewed themselves as holding the expertise in their condition rather than their health practitioner because:

“(a) people with diabetes know their body responses best, (b) each person has unique responses that cannot be predicted by textbook cases and universal norms, and (c) people with diabetes have a practical knowledge that is largely inaccessible to those without diabetes” (Paterson, et al 1999, p796)

Paterson et al (1999) conclude that “it seems reasonable to infer that health care professionals who care for individuals with diabetes and other chronic illnesses should support and acknowledge both their self-management and their differentiation” (p798).

Building on these studies, we argue that there is a need to bring the person as a participant into our research rather than employing quantitative measures in isolation, and the qualitative component of the North West Adelaide Health Study is designed to do just that. Thus in this study we initially probed participants’ understandings of what having the condition meant to them, and then followed on by exploring issues relating to the management of their condition. This issue of management formed a second important dimension of the focus of our study on participants’ experiences, perceptions and understandings of living with a chronic condition.

### **1.2.2 Managing chronic conditions**

Providing patient education and information is a common strategy for the management of chronic conditions such as asthma and diabetes. However, knowledge of what should be done is not necessarily followed by actions on the part of those with the condition. Much has been written in the literature on chronic conditions regarding issues of management. This is particularly the case in relation to concerns about adherence or ‘compliance’ to health schedules in patients with asthma and diabetes, where rates of adherence are relatively low. For example, Bender, Milgrom and Rand (1997) note that non-adherence in asthma patients ranges from 30 to 70%.

In light of this incongruence between knowledge and action, it is important to qualitatively explore people’s experiences, perceptions and understandings of what it is like to live with a chronic condition, including its management, in order to better understand the decisions people make about managing their condition. In the qualitative research literature on chronic conditions it is increasingly recognised that

the personal meaning of having conditions such as asthma and diabetes “is strongly related to the patient’s self-care and to the degree of psychological and social adaptation to the disease” (Kyngas and Hentinen 1995, p734). Adherence with health schedules in particular is determined in part by the person’s individual perception of the condition and its management (Bender, et al 1997; Hjelm, Hjelm, Nyberg, Isacson & Apeqvist 1999; Leyshon 1999).

The role played by participants’ own views regarding the condition and its management in their decisions concerning adherence to health schedules, has important implications for the use of the term ‘compliance’ by many researchers in relation to people’s decisions about management. This is particularly pertinent when we consider the Oxford English Dictionary definition of this term as “an obligation to yield passively or submit to a request or command from a higher authority” (cited by Conway 1998, p1314). The term compliance therefore rejects the person’s own views and experiences in favour of the views and experiences of the health professional. In our study we reject the notion of a passive recipient of health care advice, and in this report we will therefore use the word ‘adherence’ as recommended by Conway (1998). Conway suggests that ‘adherence’ is preferable to ‘compliance’ because the implication attached to the word compliance “diminishes the patient’s autonomy when making decisions and reduces the possibility of joint problem solving based on mutual respect” (1998, p1314).

The qualitative research literature on the management of chronic conditions confirms the importance of recognising patient autonomy and respecting the views and experiences articulated by people with chronic conditions. In a review of the literature on self-care, or self-management, in chronic conditions, Chapple and Rogers (1999) noted a number of themes in their review. For example, the authors noted that there is diversity in the extent to which people wish to participate in self-care practices, that significant others have a notable influence on self-care, that social context, work place and other aspects of lifestyle impact on people’s abilities to take on advice about management, and that the timing and stage of the condition affect the efficacy of self-care interventions.

Qualitative research in the area of asthma management tends to focus on adolescent asthmatics, mainly due to the relatively high rates of non-adherence in children and young people with asthma (van Es et al 1998). In a study conducted by Slack and Brooks (1995), adolescents aged between 13 and 17 years who were receiving drug therapy for their asthma participated in focus group interviews. The participants

discussed issues of management in three broad areas, namely the physical characteristics of the drugs, issues relating to remembering to take their medication, and the issue of the reactions of others when taking medication in public settings. The authors conclude that:

“The teens wanted to manage their medications themselves, and they consciously disobeyed adults or broke rules if obedience or the rule impinged substantially on their ability to manage acute asthma symptoms. ... Thus health care professionals and other adults concerned with the treatment of asthma need to re-assess the usefulness of labelling adolescents as rebellious when assisting them in the management of their medications.” (p1420).

In another focus group study exploring adherence-related behaviour in adolescents with asthma, van Es et al (1998) reported similar findings to those of Slack and Brooks (1995). The findings of the study were then used to develop an intervention program based on the experiences of the participants in the study as a means of improving asthma management.

Qualitative research in the area of management has also been conducted with people who have been diagnosed with diabetes. For many people, diabetes management requires major changes in behaviour to achieve a positive health outcome. Understanding the experiences of people who are trying to deal with these changes is important in understanding issues of management. Sullivan and Joseph (1998) addressed this need for an understanding of the experience of behaviour changes when they conducted telephone interviews and focus groups with adults who were diagnosed with Type 2 diabetes. The authors explored the participants' behaviour change expectations in terms of the easiness, difficulty or impossibility of making changes in diet, exercising and monitoring blood glucose. The results of this study indicate a variation in expectations with regard to disease management.

The results of Sullivan and Joseph's (1998) study support a significant theme that is emerging from the qualitative studies of diabetes management, namely the importance of addressing the issue of the effect of variations in, for example, beliefs, gender, age and lifestyles with regard to the management of diabetes. For example, Williams (1999) interviewed teenagers with diabetes and their mothers in order to explore how gender and adolescence interact to effect the management of diabetes. Williams concludes that diabetes has “gendered meanings and consequently, teenage girls and boys differed as to whether or not they assimilated diabetes into their identities” (1999, p1165). In another study of adolescents with diabetes, Olsen and Sutton

(1998) noted a divergence in the experience of diabetes by the adolescents in their study, highlighting the individual nature of the participants' experiences. The authors conclude that:

“The context-specific, and highly individual, ways in which these patients characterized the importance of friends and family should alert us to the dangers of using too simplistic a model of adolescence in professional support of young people.” (1998, p37)

In a Finnish study of self-care in adolescents with diabetes, Kyngäs and Hentinen (1995) divided their participants into four groups based on the following categories of behavioural pattern: good compliance, imposed compliance, conscious non-compliance, and non-compliance. Their conclusion reflects the importance of considering lifestyle issues in diabetes management:

“A very important finding in the present research is that patients need to feel that compliance and its aims are achievable and meaningful within their lifestyle. This is a major factor in influencing compliance with the health regimens prescribed for adolescents with diabetes.” (1995, p734)

Another area in which differences between diabetics can have a significant effect on management is where there are differing belief systems, such as in the case of immigrants. In a Swedish study exploring beliefs about health and illness in a sample of migrant Yugoslavian and Swedish diabetic women, Hjelm et al (1999) suggest that:

“in the care of diabetic individuals from different countries it is important to practice highly individualized care, also taking into consideration cultural values, migratory experiences, level of knowledge and patients' different expectations of the health care staff, especially concerning self-care and care-seeking.” (1999, p1157)

Overall, the literature on the management of chronic conditions suggests a more individual and less global approach to assisting people to manage their condition. Part of this approach involves understanding people's perceptions of the risks associated with their condition, and what they do as a consequence of those perceptions.

### **1.2.3 Chronic conditions and risk**

An important aspect of living with and managing a chronic condition is the concept of risk and risk-taking behaviour in relation to the condition. Lupton (1999), in her book

outlining the various approaches to theorising risk, divides these approaches into two categories. The first category includes those approaches that follow the *cognitive science perspective*. Within this perspective risks are viewed as objective facts, defined as “the product of the probability and consequences (magnitude and severity) of an adverse event [i.e. a hazard]” (Bradbury 1989, cited by Lupton 1999, pp17-18). Approaches that fit within the cognitive science perspective tend to view lay perceptions of risk as inferior and unsophisticated, and therefore behaviour such as ‘non-compliance’ with management schedules tends to be viewed pathologically. The second category of approaches to theorising risk are those that fit within *sociocultural perspectives*. Sociocultural perspectives emphasise “the social and cultural contexts in which risk is understood and negotiated” (Lupton 1999, p24).

Rhodes, Stimson and Quirk (1996) consider the theories of risk that fit into Lupton’s (1999) category of cognitive science perspectives to be inadequate to explain the social realities of risk behaviour, noting that the cultural and social aspects of risk need to be taken in to account. These authors note the importance of sociological and anthropological research, as well as epidemiological research. Sociological and anthropological research:

“aims to describe the personal and social meanings attached by individuals and by groups of individuals to specific behaviours categorized as “risky” by the epidemiologist.” (Rhodes et al 1996, p387)

Heyman (1992), too, emphasises the importance of taking into account and valuing lay perceptions of risk as a means of enabling health professionals to assist clients in managing risk. This taking into account and valuing of lay perceptions requires the use of qualitative approaches as a means of exploring the ways in which people experience, understand and manage areas of their lives that are defined as ‘risky’ by professionals. When it comes to the issue of ‘non-compliance’, Heyman concludes that “those who dismiss defiance of official preventative advice about smoking, the use of illicit substances or sexual contact as non-compliance risk overlooking or misunderstanding decision-makers’ own rationality” (1992, p20). In other words, it is imperative that we explore the ways in which people with chronic conditions understand and experience risks from their own perspective. This understanding of risk can then inform strategies for the management of chronic conditions.

### 1.2.4 The present study

In order to develop and improve our understanding of chronic conditions and their management, it is important to explore the myriad ways in which people with chronic conditions understand the various aspects of the condition in relation to their own life, their beliefs, and their perceptions. As outlined above, a number of researchers have qualitatively examined the meaning and experience of chronic conditions and the management of these conditions from the consumer/patient's perspective in a variety of settings (Kaufman 1988; Kyngas and Hentinen 1995; van Es, le Coq et al 1998; Hjelm et al 1999). The present study continues this research tradition through the qualitative exploration of the experiences, perceptions and understandings of chronic conditions and the management of chronic conditions by people with asthma and diabetes in the north west region of Adelaide. The study further incorporated explorations of the experience and understanding of risk from the perspective of the study participants.

### 1.3 Aims of the study

In this small-scale study, we aimed to interview a sample of people who took part in the biomedical part of the North West Adelaide Health Study and who were identified as having either asthma or diabetes. Specifically, the study aimed to qualitatively explore their experiences, perceptions and understandings of what it is like to live with a chronic condition in terms of:

- the experience of diagnosis;
- perceptions and understandings of current health status;
- the meaning of having the condition to the person's life;
- the experiences, perceptions and understandings of management issues;
- risk perception in relation to the condition; and
- the role of health professionals in the management of the condition.

At the end of the interviews participants were also asked about their experience of participation in the North West Adelaide Health Study. This was done in order to identify strategies for improving the viability of the cohort study based on data gathered directly from study participants. These results are reported elsewhere (Cheek and Oster 2000).



## **CHAPTER 2: METHODOLOGY**

## 2.1 Methodology

The study was exploratory and interpretive in nature. It involved ten semi-structured in-depth interviews with participants in the North West Adelaide Health Study who were diagnosed with asthma or diabetes. As noted previously, this study formed a qualitative part of a larger epidemiological study. The qualitative aspects of epidemiological studies can enrich the quantitative data, and in turn indicate areas that may be quantified such as the distribution and range of perceptions and understandings of living with a chronic condition within and between groups of individuals. This is discussed further in the discussion section of the report.

### 2.1.1 Ethical considerations

Ethical approval was sought and granted through both the North Western Adelaide Health Service Ethics of Human Research Committee, and the University of South Australia Human Research Ethics Committee. Access to participants was gained through the biomedical part of the North West Adelaide Health Study. Participants who expressed an interest in participating in the in-depth interviews were given an information sheet (Appendix 1) that explained what the study was about, and they were then asked to sign a consent form (Appendix 2). The participants were asked for permission to pass on their contact details (phone number and address) to the qualitative research team at the Centre for Research into Nursing and Health Care, University of South Australia, who could then contact them to organise an interview time. The interviews were conducted at a location chosen by the participants. Most of the participants (8 out of 10) chose to be interviewed in their own homes, while two chose to be interviewed in a private meeting room at the University of South Australia.

Participants were assured in both the information sheet and at the start of the interview that their anonymity and confidentiality would be maintained at all times. They were also informed that they were free to withdraw from the study at any time or refuse to answer questions without their relationship with the North Western Adelaide Health Service or the University of South Australia being affected.

All identifying details have been removed to ensure the participants' anonymity. All data has been stored in accordance with the current National Health and Medical Research Council guidelines.

## **2.1.2 Sample**

Purposive sampling techniques were used in order to ensure information-richness. Information rich cases are “those from which one can learn a great deal about issues of central importance to the purpose of the research” (Patton 1990, p169).

### **2.1.2.1 Recruiting the sample**

Participants of the North West Adelaide Health Study who attended the clinic (the part of the study where they were assessed on a variety of biomedical tests) and had a diagnosis of asthma or diabetes confirmed by a doctor, were informed about the qualitative interviews and asked if they were interested in participating. Once ten participants had given their consent to participate, their contact details were forwarded to the qualitative research team. These participants were then contacted and a suitable interview time was established.

### **2.1.3 Demographics of the sample**

The clinic team attempted to gather a sample that incorporated a variety of age groups, an equal number of males and females, and an equal number of people with diabetes and asthma. Ten participants took part in the interviews. Five were diagnosed with asthma, and five were diagnosed with diabetes. There were two males and three females with diabetes, and two males and three females with asthma. The participants ranged in age from 19 to 83 years.

### **2.1.4 Data collection: the in-depth interview**

Face-to-face in-depth interviews were conducted to explore the experiences, perceptions and understandings of living with a chronic condition. In-depth interviews are “directed towards understanding informants’ perspectives of their lives, experiences or situations as expressed in their own words” (Taylor and Bogdan 1994, p77). The interviews were semi-structured around an interview schedule (Appendix 3). Semi-structured interviews refer to those interviews in which “a direction is given to the interview so that the content focuses on the crucial issues of the study” (Burns 1997, p330).

The interview schedule was developed based on the literature in the area of qualitative research into chronic conditions. Participants were encouraged to talk about their experiences, perceptions and understandings of living with a chronic condition. The

interviewer probed for responses relating to the issues identified in the aims of the study, namely:

- the participant's experience of diagnosis;
- their perceptions and understandings of current health status;
- the meaning of having the condition to the participant's life;
- their experiences, perceptions and understandings of management issues;
- their perception of risk in relation to the condition; and
- the role of health professionals in the management of their condition.

The interviews were audiotaped and transcribed ready for analysis.

### **2.1.5 Data analysis**

The research team (JC and CO) independently reviewed each transcript. The analysis broadly followed the four stages identified by Ekman and Segesten (1995):

- the entire material collected was studied to give a sense of the whole;
- themes and categories were identified;
- recurrent patterns were identified;
- summative themes and research findings were developed.

The reviews were exchanged and any disagreements were discussed and resolved by consensus. Themes and issues across interviews were generated and these were then progressively grouped into categories of similar themes. Major categories of themes or issues pertaining to the experiences, perceptions and understandings of living with a chronic condition were produced as a result of the analytic process.

## **CHAPTER 3: FINDINGS**

Before we go on to discuss the findings of the study we would like to make a couple of qualifications. Firstly, this was a small-scale study involving ten participants with particular conditions (i.e. diabetes and asthma). Secondly, the study was conducted in a particular place and time. The study findings are therefore not intended as generalisations of the experience of chronic conditions across populations. We do not make these qualifications as a means of discrediting the findings. Rather, we would like to point out that without small-scale studies such as this, possibilities for research would be so limited as to make the task of researchers almost impossible. The findings of studies such as this are capable of providing a unique insight into the experiences, perceptions and understandings of the participants in the study, as well as contributing to a broader understanding of the experience of chronic conditions in general. These findings can provide a platform for future research and enable the refinement of existing research techniques.

The findings of the study are presented according to the format of the interview protocol. The interviews were conducted in a semi-structured manner in which we were seeking rich, exploratory, discursive data about participants' thoughts, feelings and perceptions about the condition, its management and the notion of risk in relation to the condition.

### **3.1 Initial diagnosis**

We began the interviews by asking the participants to talk about the time when they were first diagnosed with the condition. The findings in this section focus on the participants' articulated experiences of diagnosis.

#### **3.1.1 The diagnosis**

When asked about the experience of being first diagnosed with a chronic condition, the participants with asthma replied predominantly that the diagnosis occurred when they were children, and was generally associated with lung infections and colds. One participant remembered lying in bed thinking, "I'm going to die". Another remembered having asthma as a child until the age of fourteen years when, to use their words, it "disappeared" only to return when they were in their early twenties. This participant noted: "I've had a few good healthy years away from it." The only participant who did not remember asthma being first diagnosed as a child said that they were about 30 years old and the diagnosis of asthma was associated with having a cold.

On the other hand, those participants with diabetes tended to be diagnosed later in life, and hence the person was older at the time of initial diagnosis. Most of the participants with diabetes had suspected that they had diabetes due to the symptoms that they had been observing. One participant noted that they had felt tired, thirsty, and out of sorts. Another participant said they had a dry mouth and that they were thirsty. Another had found out about their diabetes as a result of allergy blood tests.

There is therefore a difference between the participants with asthma and those with diabetes, in that those with asthma tended to experience their first diagnosis in childhood. The symptoms were often not initially diagnosed as asthma, but rather as just a bad cold or other infection, which later was diagnosed as asthma. On the other hand, the diagnosis of diabetes tended to be associated with being older, and in most cases diabetes had been suspected due to symptoms. All the participants had some concept of their first diagnosis, although this concept was somewhat hazier if it had occurred in early childhood.

### **3.1.2 Thoughts and feelings at initial diagnosis**

When asked about their thoughts and feelings at the time of the initial diagnosis, participants related the following thoughts and feelings. Some participants described feeling a sense of shock. As one participant noted: “I was rather shocked and thought how I was going to be affected. That hit me.” So consequently for participants a question that was high in their minds was how this diagnosis would affect them. Furthermore, some participants said that they went into a state of almost denial, a feeling that “It can’t be true.” As one participant put it: “I thought it was a misdiagnosis. I just thought it was a chest infection, and you know, something associated with the cold, and I never really related it to asthma at that stage.” However others said that they felt, due to their family history, or their experiences of knowing people with either asthma or diabetes, that they had almost expected it, or knew what was coming. According to one participant: “My mum’s got it, so I was bound to get it. My sister gets it, so I knew it was coming.”

One participant recounted feeling that they were going to die, a fear of the fact that they might die, and experiencing intense pain associated with their chest infection. Another recounted the feeling of being stuck with this “thing”, and unable to escape. As they put it: “Basically I thought, I’m going to be stuck with this the rest of my life, and I’m not going to be able to escape it, and it’s going to stop me doing stuff that I want to.” Further, several participants stated that they didn’t really know what

it was that they were being diagnosed with. As one participant saliently put it: “Vaguely I guessed at that time it was like asthma, I’ve got asthma, but I didn’t really know what it was all about, except I had to take medicine. But then I had taken medicine from such a young age. I was always on tablets as a child”.

The range of thoughts and feelings identified by participants in these interviews are summarised in Table 1.

**Table 1: Initial diagnosis**

<b>Initial diagnosis</b>	
<ul style="list-style-type: none"> <li>• I’ve got it but I don’t know what it is</li> <li>• Stuck with it – can’t escape</li> <li>• Shock</li> <li>• How will this affect me?</li> </ul>	<ul style="list-style-type: none"> <li>• Denial – can’t be me</li> <li>• Pain and fear of dying</li> <li>• Knew it was coming – sort of expected it</li> </ul>

### 3.2 Living with a chronic condition

The interview then went on to probe the thoughts and feelings of the participants about living with their particular chronic condition. The themes that emerged from the analysis of this aspect of the interviews are represented in Table 2. Each theme is then discussed below.

**Table 2: “It’s always in the back of your mind”**

<b>“It’s always in the back of your mind”</b>	
<ul style="list-style-type: none"> <li>• A battle</li> <li>• An ever present burden</li> <li>• Not being normal</li> </ul>	<ul style="list-style-type: none"> <li>• The ‘niggly’ things</li> <li>• Just going along with it</li> <li>• Dealing with others</li> </ul>

### 3.2.1 It's "always in the back of your mind"

The overriding theme to emerge from participants' views about their thoughts and feelings was that the condition is something that is always "there". As two participants put it, it's "always in the back of your mind." Themes that fed into this overarching idea related to various aspects of the condition always being in the back of their mind.

#### **A battle**

Some participants spoke of their experience of living with a chronic condition as a battle. As one participant put it: "As they say, battle on, cherry on. Without putting too much effort into this, I realised that is the whole crux of the matter." It was as though it was the participant versus the chronic condition, the symptoms versus the management, and the condition that was always 'out there' versus what is happening to them. As one person with diabetes explains: "Oh, me against diabetes, its symptoms and its - what would you call it? Not cure. How would you explain it?"

The battle not only related to the participant fighting or coming to terms with their chronic condition, it also related to the battle involved in having to accept that they actually had the condition and acknowledging that the chronic condition was real. This reflects the notion of transformational experiences reported in the literature, where these experiences result in a transformation from one way of 'being' to another, involving restructuring of both the experience of the condition and of the 'self' (cf. Paterson et al 1999). One participant put it so effectively when they said: "Look, I really don't, I don't know whether, perhaps I don't want to accept it, and if I do, then I'll really think perhaps there really is something wrong with me when I start going there [to the diabetes clinic]."

Thus this living with the condition was experienced as a battle once there was acknowledgment that the chronic condition did exist and that the person had it. However, there was also a battle on some participants' part before that, a battle relating to getting to the point where they could actually accept that they did have the condition.

#### **An ever present burden**

An associated theme of something always in the back of one's mind, was the sense of the chronic condition as being a burden that was always present. Participants spoke of the chronic condition in terms of it removing pleasure from their lives. As one

participant said: “It has taken some of the pleasure out of life for me. I have to say that.” Participants spoke of not being able to enjoy life. They spoke of the fact that, for instance, “you can’t simply go out and have a meal if you have diabetes, because there are different things you can’t eat, so you more or less stop at home.”

Associated with this notion of the condition as an ever present burden were feelings of not being in total control, seeming at times that life was out of control, that it was all just too hard - too much of a burden. In addition there was a sense that it was an unjust burden. As one participant put it: “It’s not fair.”

People spoke of the fact that the only thing they were able to do was to try to manage their condition by either taking certain tablets or medications, or not doing other things such as not eating some things, or not doing certain activities that may cause attacks. Some of them considered this to be another form of burden. As one participant put it: “I’ve got to remember to do this and do that. It’s too much of a hassle really. When it comes down to it like, I’d love to, I’d love to just sort of have a normal life.” In fact, many participants spoke of hassle as associated with the burden of living with a chronic condition, and as one participant noted: “Sometimes you think oh, I just can’t be bothered.”

### **Not being normal**

Another associated theme was the feeling of not quite being “normal”, as participants termed it. One participant spoke of the condition as a handicap. Another commented, “It’s just a test from God.” This participant used vivid images of their bodily decay to talk about the condition and what it was doing to their body. They almost wistfully stated that if they were normal, they might be able to do other sorts of things. Indeed, for many participants there was an awareness of the fact that they were different from other people. As one participant put it, they felt different “just knowing that I may be different from other people because that’s how I wake up every morning really.” Further, they didn’t quite know how to describe themselves, or what part of the condition was of ‘themselves’. Thus they didn’t know whether to call it a disease, an ailment, or whatever. For many of them, this “thing” that created this sense of not being normal was viewed as being “out there somewhere”, so it was possible for one participant to speak in terms of having a few good healthy years away from “it”.

### **The ‘niggly things’**

A further related theme was the “niggly things” that people identified as always having to be kept in the back of one’s mind. As one participant put it: “I know it’s

stupid, but you know there's all these little things, niggly things." People spoke of the chronic condition in terms of it being a nuisance, of being awkward, restrictive, annoying, limiting, or worrying. According to one participant: "It's just a blooming nuisance." Another participant said: "It is just so inconvenient, you just get flustered. You have to make sure to get the puffer out of the bag in time before you pass out or something."

One of the participants who was elderly spoke of the fact that it was these "niggly things" that increased her anxiety level and her worrying. She said: "Living on your own, and things go wrong you know, you've got no one to call ... Quite alright, but I suppose I am a bit of a worrier and I just have time to worry about little things that are perhaps unnecessary."

So for all of the participants there was a sense that these "niggly things", these little everyday minutiae, these somewhat mundane things, were always in the back of their mind, and that they were things that constantly reminded them of the fact that they were having to manage a chronic condition.

### **Just going along with it**

Another powerful theme to emerge from this "thing" always being in the back of your mind was participants' sense that you just have to go along with it. First of all they spoke of the fact that you just need to go along with it in the sense of needing to acknowledge that you have the condition. As one of them put it: "I really need to get my act together, and acknowledge that I have it. It's not going to get better unless – well, it won't get better. You are always living with it, I suppose, but the symptoms would improve I think." Once one could go along with the fact that one had the condition, i.e. having acknowledged it, then it might be possible to grow "accustomed", to use another participant's word, to having it. Participants spoke of the need of having to adjust and accept both the fact that one had the condition, and that it was going to be part of their life. As one participant noted: "You just get used to it. You learn to live with it." Learning to live with the condition, and just going along with it, involved, on some participants' part the acknowledgment of the fact that they are going to have to, to quote one participant: "Suffer a bit to be happy in my job. I'd have good days, I'd have bad days."

Participants spoke of the fact that just going along with it required patience and tenacity. As one participant commented: "You don't give up" One participant had probably got to the point where they had managed to "just go along with it" so much

they admitted that they probably didn't even think of themselves any more as, to use their words, "an asthmatic". This participant didn't feel that they were an asthmatic: "Because I just don't suffer or consider that I suffer as much as a person who really has the disease as such."

**Dealing with others**

When discussing their thoughts and feelings associated with living with a chronic condition, participants also spoke of their experience of dealing with others as a result of their having this condition. Participants identified that there were two sorts of "others" that needed to be dealt with. There were those "others" who were also diagnosed with the chronic condition, and those "others" without it. This notion of dealing with these two groups of "others" is summarised in Table 3 and discussed below.

**Table 3: Dealing with others**

<b>Dealing with others</b>	
<p><i>Others with the chronic condition</i></p> <ul style="list-style-type: none"> <li>• Identify with those who have it</li> <li>• Empathy and support from others</li> <li>• They can appreciate what I feel like</li> <li>• Good to share ideas and experiences</li> <li>• Can talk to others with "it"</li> </ul>	<p><i>Others without the chronic condition</i></p> <ul style="list-style-type: none"> <li>• They don't understand that I can't do things</li> <li>• They don't understand what happens to me</li> <li>• Treated unfairly by them at times</li> <li>• Others need to learn about it, experience it and understand</li> <li>• Hard to explain to them</li> </ul>

Participants spoke of being able to identify with those who had the chronic condition, and of receiving empathy and support from those people. They felt that people who had the same chronic condition could appreciate, to some extent, what they themselves were feeling, and that it was good to be able to share ideas and experiences by talking to people who had that chronic condition.

On the other hand, participants did not necessarily find it easy dealing with others without the chronic condition. Some participants spoke of people without the chronic condition as not understanding either what the condition was, or what they might expect from that chronic condition. For instance, one participant spoke of the fact that he had gone into a diabetes-induced coma, but had mistakenly been thought drunk by others. Others felt that they had been treated unfairly by people without the chronic

condition, believing for instance that they had been “knocked back” from jobs, that they had been unfairly treated with insurance policies, and so forth. As one participant put it: “It’s hard if other people don’t understand why”. Understanding “why” related to all sorts of aspects of their life. For instance, one participant noticed: “When they visit and they want to press the cakes and things on you, and you have to decline and they don’t understand why, they think they shouldn’t make any difference, but because I’m on a strict diet, it affects me more than if I was on insulin.” A few participants felt that some people just simply couldn’t put up with somebody who was perceived as different.

Participants felt that it would be good for others to learn about these chronic conditions, to somehow try to gain some empathy and understanding of what it might be like to have the condition. One participant felt that it might be easier for others without a chronic condition to identify with asthma as opposed to diabetes, since asthma was well known and advertised, stating: “Everyone can identify with it and understand. Even if they don’t have it, they can empathise with you and say ‘I sort of understand what you are going through’, so yes.” Another participant felt that ‘others’ without the condition may be more understanding if they already knew someone with the condition: “Yes, if they help you then you are more confident, but if, you know, you don’t get any help, that’s not good either, but he [husband] understands. His auntie is a diabetic too.”

In most cases participants felt that they could relate better to those who had had the condition, than those who hadn’t, particularly with respect to talking about treatment and about the management of their condition. This is well summarised by the following quote: “I’ve always sort of felt different. Like if I ever talk to other asthmatics they can sort of understand, and they can appreciate what I feel like, but if I talk to, say, my boyfriend about it, he can’t really understand what it’s like. It’s hard to explain.”

### **3.3 Managing a chronic condition**

Participants were then asked to discuss the management of their condition. They were asked about the kinds of things they had been told to do, and about how they find managing the condition.

The next part of the analysis pertains to issues analysed from participants’ responses relating to the management of their chronic condition. This section on participants’ management of their condition has been divided into two parts. The first part looks at

participants' experiences in relation to the interactions that they have had with health professionals in terms of the management of their condition, and the second part relates to their experiences of the self-management of their condition.

### 3.3.1 “They only ask what’s wrong”: the need for health professionals to have the whole picture

In this section we look at what participants said about their experiences of managing their condition with respect to their interactions with health professionals. The analysis of participants' responses resulted in the emergence of a major theme that related to the fact that there was a need for health professionals to have the whole picture. As one participant put it: “They only ask what’s wrong.” In other words, what participants were saying, and this participant in particular, is that health professionals often don't have the whole picture.

In terms of having the whole picture, participants' responses can be divided into three main areas. This is summarised in Table 4:

**Table 4: “They only ask what’s wrong”**

<b>Need for good information and communication skills to convey and explain that information</b>	<b>Having time</b>	<b>Being interested in me</b>
<ul style="list-style-type: none"> <li>• Hard to talk to</li> <li>• I don't tell them the whole truth</li> <li>• Unclear</li> <li>• Didn't listen</li> <li>• Communicating at an appropriate level</li> <li>• Feeling comfortable to discuss what I've found out</li> <li>• 'They know best' attitude</li> <li>• A dummy</li> <li>• Feel like being judged</li> <li>• Weigh up how credible GP information is versus own experience</li> </ul>	<ul style="list-style-type: none"> <li>• Whip you in, whip you out</li> <li>• Going through the motions</li> <li>• Need to be thorough and do the whole bit</li> <li>• No patience</li> <li>• Client in a hurry too</li> </ul>	<ul style="list-style-type: none"> <li>• They don't have the condition</li> <li>• Don't ask why?</li> <li>• Assume they know everything about you and your condition after 20 minutes</li> <li>• Lack of continuity in health professional care sometimes</li> </ul>

Each of these three areas pertaining to having the whole picture are now discussed.

### **The need for good information and communication skills**

The first area related to the need for good information and communication skills to both convey and explain the information given. Many participants talked of health professionals as being hard to talk to, and not wanting to listen. They felt that not only did doctors or the health professionals not want to listen, but when explanations were given they were not necessarily at the appropriate level. For example, one participant said: “I found they were all talking above my head. They are using these big flaming words and yet they weren’t speaking English. I thought ‘This is all beyond me.’” However, wanting simplicity did not mean that participants did not require large amounts of information. Participants did want to know about their condition. They wanted to know what their options were, and they wanted to know how to manage their condition. They wanted to feel comfortable, to be able to discuss issues relating to the condition with their own health professional, who in most cases was a general practitioner (GP). In many instances that comfort level did not exist. As one participant put it: “There seemed to be a bit of a communication breakdown. I didn’t feel like I could sit and sort of have a proper discussion about my condition, and yes, I guess my sole purpose was really going and getting the antibiotics, and once I’d got a prescription for that, I’m satisfied with my consultation.”

Some participants referred to the fact that they felt like the health professional assumed that they (the health professional) knew everything, and that the participant did not know very much. In terms of knowing everything, the following interview extract sums up much of what most participants were saying: “I think most of them haven’t really got enough time to do it. Like, if you are lucky you might talk for 20 or 30 minutes in one session, and after that they assume they know everything about what you are trying to get across, and unless something drastic happens, they don’t really want to know. Like you just can’t get in because they haven’t got the time, and usually then they go on what you tell them, or what you feel like.” In addition, they felt like they were being judged to some extent. As one participant commented: “You feel that in some ways someone is going to make some judgmental sort of things about your behaviour or smoking, and so you feel that you needed to do something about that before you even got there.” In fact, some participants said they did not disclose the whole truth to their health professional because either they didn’t have time, or they felt like they were going to be judged.

Many participants spoke of the fact that they would weigh up how credible the health professional’s information was, as opposed to their own experience. What this

highlighted was the need for good information, but more than that, the need for good communication skills to convey and explain that information. The elements of those good communication skills were described as follows:

- the level of comfort in the health professional's office;
- the ability to be able to talk to, and with, the health professional;
- the ability of the health professional to make the participant feel comfortable to discuss both what they were feeling about their condition, and also information they may have found out about the condition, in order to weigh up whether or not that information was credible; and
- the ability of the health professional to appear non-judgmental and to avoid making the participant feel like they were being judged.

### **Having time**

An important part of health professionals having the whole picture was the health professional actually having time to get the whole picture. One participant put it this way: "I guess there are some GPs you could sit down with, but it hasn't been my experience that I could sit down and have a discussion with a GP. I feel like you are using up their time, and they want to whip you in and whip you out. I don't think they are really interested in your little lay person's opinion about things, I guess, to a degree." Many participants expressed, in different terms, this sense of being herded in and herded out. Another participant described it as simply going through the motions in order to get the prescription and get out of the general practitioner's office as soon as possible.

Participants spoke of the fact that some health professionals had little patience, and certainly didn't seem to have any time for detailed discussion. However, some participants noted that they themselves were often also in a hurry, and they perhaps didn't have time to sit down and discuss their condition. As one participant put it: "Perhaps that's my fault that I don't spend a bit more time, you know, I'm always in a bit of a hurry as well. Yes, perhaps they don't ask a question, and because I'm not severe and I'm not complaining, then they think everything is fine, so perhaps there is a bit of fault there with me as well." What participants seemed to want more than anything was for doctors or other health professionals to take the time to be thorough. Participants wanted health professionals to communicate well and inculcate a sense of confidence in the participant that their condition was being managed, that somebody did care about their condition, and did know what was happening.

### **Being interested in “me”**

The third and final area that fed into the need for health professionals to have the whole picture related to the issue of being interested in the patient. This was an overriding theme, namely the need for a health professional to be interested in “me”, the person with the condition, not just the condition itself. The participants spoke of the fact that they felt that most health professionals did not have the condition themselves, and so consequently they found that sometimes they did not have the same sort of empathy with them as they might have with a health professional with the condition.

Participants found that health professionals didn't ask why things were happening, why people were behaving in the way they were, or why they weren't managing. We go back here to the quote already cited where one participant put it that health professionals assumed that they knew everything about the patient and their condition after 20 minutes. There was a sense of the fact that there was little interest in them as a person. As one participant put it: “They write you out a script, whiz you out and get your money, and I don't ever feel like they are interested in me.” And again: “I'd expect more than them just writing out a prescription you know – listening to your chest, writing out a prescription, and sending you on your way. I would expect them to find out a few questions about your lifestyle and what affects your asthma. It's really by the amount of detail they ask and asking the right and appropriate questions.” This individual commented on the fact that he had turned up to a consultation with a cigarette packet noticeable in his pocket, and had not even been asked about it by his health professional. Participants also spoke of the fact that it is difficult to find a health professional that they could see on a continual basis, given the nature of modern practice in many instances. They felt there was a lack of continuity in health professional care at times.

Perhaps the best summary of this theme about being interested in “me” comes from one of the participants who said: “I think the main thing is to sit down – I mean it would take a long time, but the main thing is to find out everyone's circumstances. Find out where they live, who they live with, what their circumstances are, where they work, because that all, when it comes down to it, that all combines to make an asthmatic person different from another asthmatic person. If doctors are to plan out this asthma management plan, it needs to be very, very personalised, and they need to sort of dig into the person they are doing it for, and find out exactly what goes on in their lives.”

Thus the picture that emerged in terms of the theme of the need for health professionals to have the whole picture is of people who consult health professionals wanting to be recognised as “me with the chronic condition”. They want to be recognised as a person to communicate with, and want to participate in information sharing and communication with a health professional. Central to this is the health professional being able to spend time with them in order to discuss the condition, and the management of that particular condition.

### 3.3.2 Managing one’s self

Having discussed participants’ interactions with health professionals in terms of the management of their condition we now turn to participants’ experiences of the self-management of their condition. With respect to self-management, most of the participants’ responses could be distilled into the notion of ownership of the condition. “It’s mine” as one said, “because I lived it.” Related to the idea of ‘It’s mine and I need to manage it because I live it’ were three themes. These can be seen in Table 5:

**Table 5: Managing one’s self**

<b>It’s mine: “Because I lived it”</b>
<ul style="list-style-type: none"> <li>• Taking/accepting individual responsibility for the management of the condition</li> <li>• Management as very personal and individual</li> <li>• Being in control</li> </ul>

#### **Taking/accepting individual responsibility for the management of the condition**

The first theme relating to the ownership of the condition was the need to take and accept individual responsibility for the management of that chronic condition. As one participant said: “You have to be strong, and you have to be aware and alert.” All participants spoke of the fact that they themselves needed to cope with the changes that had been enforced upon them, that they had to adapt their lives, and that they had to accept that they actually had the condition, and because of this they need to do certain things. They spoke of the need for self-surveillance, accepting responsibility for that surveillance and then managing the condition appropriately. For instance, one participant talked about constantly checking things “like what to eat, check your feet, and things you know, don’t walk barefoot or things like this. Don’t step in, if you step in something, just clean it proper, just check all step. Just to keep an eye on feet because it can get ulcers (sic).” Some spoke about the fact of needing to feel secure

and reassured by the way that they managed their condition. For instance, knowing that their asthma puffer was always in their handbag, and doing things just to take a load off their mind.

### **Management as very personal and individual**

Related to this idea of self-management in terms of the condition being ‘theirs’, was the fact that any management of a chronic condition is going to be very personalised and individual. Prominent in participants’ discussions regarding issues of management was an awareness of the fact that everyone is different, and that it is important to always be aware of these differences. Participants spoke of the fact of needing to learn how to deal with their own condition themselves. As one participant described it: “Learning for your own personality.” People are different and they do in fact do things differently. Furthermore, the manifestation of the condition itself may be different as well. As one participant put it: “Everyone’s case of asthma is different, so it’s not ‘You can just say this is asthma, and this is what it is’ because it is different, it’s so personalised.”

### **Being in control**

Finally, in terms of this theme of ‘it’s mine because I lived it’, being in control was an important part of the management of the condition by the people concerned. This notion of ‘being in control’ was seen by the participants in terms of the fact that they could manage their condition, and that they could make decisions such as when to seek help. Furthermore, being in control was related to issues of ownership, because as participants said, “if you've got the problem, then that’s a problem to you”. Participants felt that being in control involved being able to have some input into the management of the condition, even if it wasn’t to take total control of that management, but to at least have input and feel like they had input. As one participant said: “I like to take responsibility for these things myself, and not just depend on everyone else for them, and to me that is the first step in managing your own environment.”

Further, participants spoke of knowing at times what their body was doing and how they felt, more than any management regime set down by a doctor or a health professional. As one participant said: “I don’t know how long you have been a doctor. You are telling me I’ve got to take them [tablets]. I say I don’t want any more. If I die, I die of my own will because I’ve had this longer than you’ve been a doctor.” Furthermore, as another participant said, they “take their medication or whatever, when I need it. You know, I guess, it’s just knowing the signs.” Thus

many participants felt that learning how to manage their condition involved learning what to do, and knowing if it worked by how it feels. As one participant said: “I know my body better than a doctor, and I’m a firm believer in thinking that I’m a better healer of myself than maybe what a doctor is of me, because they are not inside of me. They don’t know how I feel.” This last comment sums up much of what we have been talking about in terms of participants’ experiences of the management of their condition.

Thus managing the condition from participants’ perspectives is more than just preventing the condition or prescribing medications to control that condition. Participants felt that managing the condition also related to the fact of accepting the person with the condition as part of the management, involving that person in the management, and recognising that because the people involved are individuals, there can be no standard pattern of management. Rather, there needs to be accommodations made for the individuals concerned.

### 3.4 Risk

The final part of the interview explored participants’ perspectives about risk in terms of their chronic condition, and whether or not they believed that they took risks related to their health.

#### 3.4.1 “... it’s a bit of a balance”

Analysis of the participants’ responses to the question of risk revealed a central theme of risk being a bit of a balance. As one participant said: “So I guess it’s a bit of a balance, like you don’t want to restrict your lifestyle too much, but you also don’t want to affect your health.”

Related to this central theme of risk being “a bit of a balance” were three contributory themes. These were: doing the wrong thing, weighing up the consequences, and the immediacy of the perceived risk, that is, whether or not the risk seems real or serious.

This is summarised in Table 6:

**Table 6: “It’s a bit of a balance”**

<b>“It’s a bit of a balance”</b>
<ul style="list-style-type: none"> <li>• Doing the wrong thing</li> <li>• Weighing up</li> <li>• Immediacy – seeming real or serious</li> </ul>

We turn now to discuss each of these contributory themes in their own right.

### **Doing the wrong thing**

Risk was often defined by the participants as “doing the wrong thing.” For example, participants spoke of the actions that they equated with taking risks as cheating. As one participant said: “I keep saying to myself, ‘I mustn’t do this, or only do it say once a week’ but it’s probably nearly every day that I will have things that I shouldn’t have. But on the whole, I do try, but not hard enough.” Others just said that despite the fact that they know they shouldn’t be doing what they are doing; they “do the wrong thing” anyway. For instance, one participant described herself as not really a risk taker, even though being a severe asthmatic, she smoked many cigarettes a day. “No, I’m not a risk taker” she said, “I’m just an idiot really. I know smoking and asthma don’t mix.” Others described risk as, for instance, occasionally having a sweet when you shouldn’t. In other words, doing the wrong thing.

Some participants were quite aggressive in terms of the fact that yes, they were doing the wrong thing, and that’s okay by them. As one participant said about their smoking: “I’m not going to give it up, and that’s it. I won’t listen anyway.” Another participant said: “I’m not stopping having these goodies I like.”

It was interesting that one participant described themselves as not being a risk taker, but did in fact alter the way in which they took the medications that they were prescribed. Their rationale was that because they had had their asthma for a long time, they understood their needs, so quote: “I wouldn’t put myself in a life threatening situation – I’m a bit of a wuss really when it comes down to it. I won’t take things unnecessarily either.”

Participants said that doing the wrong thing related, at times, to the fact that they felt they were lazy, in terms of not going out of their way to do the things that they should. Participants spoke of the need for self-control, the notion of knuckling down. As one of them put it: “It’s just me knuckling down and yes, deciding for myself. I must not, you know, have anything that is going to make it worse.” This involved participants deciding for themselves what they were prepared to knuckle down and do. One participant said that they are probably being “stupid” by doing the wrong thing, but nevertheless they would continue to do so. Another participant, to use their term, considered it “irrational” to go along and see their doctor about asthma when they were smoking 35 cigarettes a day. So to them, doing the wrong thing identified themselves in their own mind as a risk taker, but also made them feel as though it was inappropriate for them to then seek health professional help for their condition.

### **Weighing up**

Another element of the ‘bit of a balance’ that constituted risk in people’s mind, related to weighing up the consequences of one’s decisions. Weighing up, as one participant put it, was seen in terms of “minimising risk versus minimising lifestyle.” As they put it: “Now you take that into consideration. Like, do you want to go in and be a total vegetable? No risk whatsoever, except to being a vegetable as against maybe trying to get through and still have a bit of concept.” Another participant expressed it this way: “You know, if I spend my whole life going ‘well, I might have an asthma attack, or I might not have an asthma attack’, but I’m never going to live my life.” And yet another participant noted: “If I take all of these precautions, how do I know that I’m not going to get sick anyway?” At the core of this was a sense of “Why bother?” impacting on the decision-making occurring when weighing up the pros and cons of certain courses of action. As one participant said: “If I could remove asthma completely, I would do this, but because I can’t, I think ‘Bugger, I’ll do it anyway’.” This idea was picked up by another participant, and sums up this whole area of “Why bother?” very well. They state: “Why bother? Sometimes you go in there and you think ‘Why bother?’ If I do this, it doesn’t seem to make any difference. You know full well in your own mind, like, you could get down to half your weight, you would most probably get rid of some of the problems, and you tend to want that at times when it doesn’t work. Then when it does work, you wind up getting sick from something else and think ‘Why bother?’ The usual stupidity of human beings.”

In other words, participants were saying that even if they took all the precautions, there was no guarantee that they wouldn’t have an asthma attack or develop a problem

from their diabetes, but there was a guarantee that they weren't going to, in their words, "live their life". Consequently they were weighing up whether the uncertainty of whether or not they would have an attack outweighed the certainty that they, in their own mind, were never going to live their life in the way that they wanted to. For example one participant spoke of weighing up risk in terms of weighing up the pleasure and enjoyment he got out of his job, working outdoors, as opposed to the fact that outdoors was not the ideal place to be working because of his asthma. He put it this way: "I suppose it was a weighing up process. I mean, there was the opportunity to move out of the nursery field and do other things, but I've been very happy with this field. It has got me a lot of study and furthered my work in it, so I decided 'No, this is the way I want it to be. I'd rather be outdoors than cooped up'." Another participant said that it was weighing up whether they felt comfortable feeling like a "geek" - this was the teenage participant - as opposed to taking risks. This participant associated some of the behaviour that they had to institute in order to avoid risk as acting or feeling like a "geek".

Furthermore, weighing up in terms of risk also related to some participants' view of their medications and preventative behaviour. One participant spoke about the fact that they used to use their preventative medication, but then it got to the stage where, in their words: "I just didn't want to take it any more." So they thought that they could just stick to the Ventolin when they felt they needed it. This participant did not consider this decision as taking a risk, but rather thought of it in terms of taking control of the management of their condition.

Another participant said that in some ways they felt that they had taken risks, but in other ways they hadn't. Again, this gives insight into the process of weighing up that was going on in many participants' minds. In this instance, the participant who had asthma was weighing up the risk involved in having a cigarette, citing that they had their puffer with them and friends who could assist if need be. In this way they felt that they would be okay if they had an asthma attack as a result of smoking the cigarette. Thus risky behaviour versus the pleasure of doing what they wanted to do was being weighed up in terms of what would be the appropriate way to behave. As they said: "If I do go out and I do have a cigarette, and I do have an asthma attack, that's my own fault. But as long as I've got my puffer there, and as long as I've got friends that know I'm asthmatic, and can look after me if something doesn't work, then I'm pretty happy with that." The participant who made that statement was a teenager, and she made the point that she felt that taking risks was normal anyway,

because in her opinion the whole point of being a teenager is the excitement of taking risks.

In terms of this “weighing up”, there was definitely an element of gambling, of considering the odds, and playing the odds. Several people spoke of weighing up the pros and cons and the likelihood of winning or losing. As one participant put it: “I suppose I gamble every day of my life, that I’m not going to have an attack, and collapse and die. To me it’s no risk, but to other people it is.” Consequently, whether or not to do certain things that may be considered to be risks, was in most cases a conscious decision by participants. Participants were “weighing up”, in their words, the effect of the behaviour versus the effect of not undertaking the behaviour or activity, in order to gain what they perceived was the most favourable outcome for themselves. It was hard for participants to determine where they should draw boundaries - where to start and where to stop in terms of the management of the condition. This uncertainty resulted because it seemed at times overwhelming that there were so many changes to be made, and no certainty that anything would come of them anyway. The only certainty was that the chronic condition was not going to go away.

### **Immediacy – seeming real or serious**

Another theme that fed into the notion of risk being a ‘bit of a balance’ was the notion that risk was perceived by some individuals in terms of its immediacy, that is, whether it seemed real or serious at that particular moment in time. One participant said that for them, the risk really did seem real, and that they would take appropriate actions to eliminate or minimise risk because they actually had an uncle who would not go for a check up, who did have diabetes, and lost both his legs. For others though, they felt that the risk was not high enough or the outcome of the risk was not bad enough to worry about doing anything about it, at least at this point. For instance, a person who had asthma and smoked 25 cigarettes a day said: “I’d have no hesitation if it was a problem, going and seeing a GP or getting a referral to a specialist if need be, but it’s just not severe at the moment for me to warrant doing that.” This participant was quite adamant that it was his decision as to when to give up cigarettes, and at this time, because he considered his asthma was not a major problem, he was not prepared to give up smoking.

Another participant, who was also a person with asthma and a heavy smoker, said that she would stop smoking when she actually had emphysema. She said: “When the doctor says to me ‘You have to give it up now, otherwise you are going to die’ then

I'll give it up". Thus it had to be an ultimatum, an almost end of the line thing, an immediate tangible risk. Consequently, there was a real sense on the part of many participants of long- versus short-term risk. There was the sense that "Nothing is going to happen immediately, so therefore I can probably continue doing the things I want to do until it comes to the point where I can't do them any more." As another participant said: "I'm not really looking ahead that far." Thus the sense of immediacy, the sense of the risk seeming real, or perhaps more importantly the outcome of the risk seeming real and serious, was a major factor in participants' sense of getting "a bit of a balance" in terms of whether or not to undertake certain behaviours, as opposed to restricting their lifestyle.



## **CHAPTER 4: DISCUSSION**

In this report we have documented the findings of a qualitative study that forms an adjunct to a large epidemiological population-based cohort study conducted in the northern and western suburbs of metropolitan Adelaide. This mixed-method approach, in which both quantitative and qualitative approaches have been used to explore major priority issues in relation to chronic conditions, recognises the value of a variety of forms of research. While epidemiological approaches have an important role to play in the research of chronic conditions, these approaches are not able to explore and access people's experiences, perceptions and understandings of what it is like to live with and manage a chronic condition. In the current health climate in which there is an increasing acknowledgment of the value and importance of understanding the so-called 'consumer' or 'patient' perspective, qualitative approaches that seek and value these perspectives can be seen to provide an important addition to the results attained from epidemiological approaches. It is important, however, to avoid simply paying lip service to the rhetoric of 'consumer perspectives' without actively engaging these perspectives to inform health care practices. In this section, therefore, we provide a discussion of the findings, as well as implications for the practices of health professionals who may be able to better assist people with chronic conditions based on the experiences, understandings and perspectives of the participants that took part in this study.

### **4.1 The need to understand the individuality of the experience of chronic conditions**

A major implication of the present study relates to the experience of chronic conditions as having aspects that are generalisable as well as aspects that are specific to the individual. There is a paradoxical implication here for health professionals in that while it is useful to take account of the general pattern of the experience of chronic conditions, it is also important that health professionals bear in mind the individuality of the experience. Both the apparent pattern and the individuality of the experience of living with asthma and diabetes are highlighted in this study.

An oft-expressed critique of qualitative research relates to its perceived inability to provide information that can extend beyond the generally small number of participants involved in the research. However, looking at qualitative research in the area of the experience of chronic conditions overall, we see a gradual emergence of a pattern to this experience. This is not to suggest that the aim of qualitative research is to produce generalisable results, rather that in looking at the research area as a whole there appears to be a pattern to the experience of chronic conditions. The aspects of this study that focused on the experience of asthma and diabetes supported the notion

of a pattern found in other qualitative studies. The ability of qualitative research to provide in-depth information that can function as an explanatory mechanism for these more generalised experiences can further be seen in this study. This explanatory function is evident with regard to aspects of the study that went beyond the experience of chronic conditions to probe issues regarding the management of chronic conditions, as well as perceptions of risk related to the condition.

In this study, our findings support the pattern of the experience of chronic conditions noted in the literature. For example, the study findings reflect the categories identified by Cleaver and Pallourios (1994) where the authors distinguished what they termed the 'essence' of being a diabetic. This 'essence' was defined in terms of:

- a) A retrospective perception of a relatively carefree life before the diagnosis.
- b) The appearance of the first symptoms and their consequences.
- c) The impact that the diagnosis had on the awareness of the subjects: this includes relief, shock, fear, loneliness and confusion.
- d) An emerging pattern of the life-world of the subjects, which includes conflict related to the body, loss of freedom, mood swings, irritability, changes in social relationships and control.
- e) Fear of the future (Cleaver & Pallourios 1994, p180).

Although we would not claim to have discovered the 'essence' of what it means to have a chronic condition, in our study of asthma or diabetes we can say that the elements identified in Cleaver and Pallourios' (1994) study resonate with the themes that emerged from our interviews.

Another consistency in the various studies exploring the experience of living with a chronic condition relates to the ways in which participants incorporate the condition into their lives and into 'themselves'. The findings of the present study endorse the notion that people with chronic conditions "interweave their lives with the experience of illness" (Kelly & Dickinson 1997, p273) and struggle to develop a new sense of 'self' (Charmaz 1987). Central to this process is the notion of transformational experiences as discussed by Paterson et al (1999), in which people see themselves as the subject rather than the object of chronic conditions, resulting in the continual structuring and restructuring of their experience of the condition and of the 'self'.

This general pattern of the experience of chronic conditions can be useful to health professionals in terms of the diagnosis and the management of the conditions.

However, the present study also emphasises the point that health practitioners need to recognise and understand the individual experiences that people diagnosed with a chronic condition may undergo. The areas of the experience and perception of management and risk highlight this issue of the individuality of the experience of chronic conditions. The present study strongly supports Paterson et al's study (1999) in which the authors note that the individuality of the experience of the condition must be taken into account by health professionals who diagnose and manage people with chronic conditions.

In terms of implications for health care practice, our study has more to contribute in this area of the individuality of the experience of chronic conditions, an area that is often spoken about but rarely incorporated into practice. In order to attend to the 'consumer/patient perspectives' we contend that health practitioners must not only listen to these perspectives, but they also need to incorporate them into the diagnosis and management of chronic conditions. In order to assist health professionals to incorporate the perspectives of 'consumers/patients', we now discuss the implications of the study findings for health care professionals.

### **4.2 Implications for health care professionals**

In the following sections, we draw out some implications for the practice of health professionals with regard to both the diagnosis and the management of chronic conditions that reflect the experiences, understandings and perceptions of the study participants.

#### **4.2.1 Diagnosis of chronic conditions**

Two important areas in the diagnosis of chronic conditions that need to be attended to by health professionals are those of support and information. These are discussed below.

##### **Support**

The range of thoughts and feelings identified by participants upon initial diagnosis give insight into the complexity of the situation and the individual nature of the participants' responses to the diagnosis. We concur with Charmaz (1987), McWilliam et al (1996) and others who have asserted the importance of identifying and exploring the perspectives and experiences of the person with any particular chronic condition. There are important implications here for health professionals

relating to the time of diagnosis in terms of the support that is provided for the newly diagnosed individual. Our study highlights that it is important that individuals being diagnosed with chronic conditions are given individually tailored support at this time, and that they are reassured that the range of thoughts and feelings being experienced by them are those experienced by many people. In other words, participants need to be aware that there is no right or wrong way to act or react.

Another area of support for newly diagnosed people may involve health professionals providing the means for them to talk to others with the condition about their thoughts and feelings experienced at this time. While participants suggested that there were problems in dealing with others who do not have the condition, our analysis demonstrates the positive ways in which most participants viewed interacting with others with the same chronic condition. This highlights the possibility for those with the particular chronic condition to be more involved in supporting individuals who are newly diagnosed and learning to live with the condition in an ongoing manner. This may be one way of overcoming what seemed, on the part of many participants, to be a sense of isolation and a sense that others do not, or cannot, really understand what it is like to have the condition. It may further make it easier for some individuals to accept the fact that the condition is real and to accept that the diagnosis will mean changes in outlook and lifestyle.

### **Information**

The issue of information is important in two ways: firstly, in terms of the information that is provided to participants and secondly, in terms of the information provided to significant others without the condition. The provision of information to people who are being diagnosed with a chronic condition is necessarily of value. What often is not addressed, however, is the individual nature of a person's response to the diagnosis and their immediate and future information needs. In light of participants' responses pertaining to the provision of information, we suggest that health professionals may need to tailor the information provided for the individual at diagnosis and beyond in terms of their individual needs and level of understanding of the condition.

The second important area is the provision of information to those "others" that the individual has to deal with. Living with a chronic condition clearly permeates all aspects of the life of the individual with the condition. The very strong and present theme "it's always in the back of your mind" demonstrated this. In dealing with others, the infringement of the condition into every facet of the person's social world

can be seen. The points raised by participants with respect to interacting with those people who do not have the condition are suggestive of a possible need to provide more targeted information and education for significant “others”. These “others” could include family members, work colleagues and so forth. This provision of information would need to be done in conjunction with the person who has the chronic condition.

#### **4.2.2 Management of chronic conditions**

Implications emerging in the area of the management of chronic conditions are most important in that inadequate management can have serious consequences for people who are diagnosed with these conditions. Traditionally, management schedules for conditions such as diabetes and asthma have been developed on a generalised rather than an individual level, leaving the individual and his or her experiences, perceptions and understandings out of the equation. The significant rates of so-called “non-compliance” with health schedules suggests that this management strategy is not effective. Participants’ discussion of issues of management and risk perception highlight the problems associated with assuming that everyone who is diagnosed with a particular chronic condition is necessarily the same. In the following sections, we discuss possible strategies for a more effective management approach in relation to the study findings.

#### **Negotiation**

Our findings agree with Paterson et al’s (1999) finding that, rightly or wrongly, participants do in fact view themselves as holding the expertise in their condition, rather than the health professional being seen as the expert. We would like to suggest that health professionals need to work with this understanding on the part of the person with the chronic condition, rather than simply dismissing it and labelling contrary behaviour as ‘non-compliant’. Health professionals need to acknowledge that the individual with the condition has a role to play in managing the condition.

Our findings support those of Bender et al (1997), Hjelm et al (1999) and Leyshon (1999), namely that adherence with health schedules is determined in part by the person’s individual perception of the condition and its management. This applies to the information about their condition that individuals bring to the health professional. It is important that such information is not dismissed out of hand. It is essential that the person with the condition feels able to put forward this information so that the health professional has an idea of what they are thinking and where they are getting

their information. Dismissing it will not stop the person from finding out information. It will simply stop the health professional being able to access that information and prevent their ability to direct the person to better information sources, to talk about the reliability and validity of the information, and to educate the person on how better to seek information about the condition. All of this is part of the partnership and negotiation that has emerged from our study as being at the heart of the successful management of a chronic condition, by both the person with the condition and the health professional involved. This notion of negotiated management supports Paterson et al's (1999) suggestion that "it seems reasonable to infer that health care professionals who care for individuals with diabetes and other chronic illnesses should support and acknowledge both their self-management and their differentiation" (p798).

Based on the findings in this study, we therefore support the position that negotiation in the development of health schedules is crucial, and that trying to force health regimes on people will not work. We are dealing with individuals who are no longer willing to be, if they ever were, passive recipients of health care that is determined by others. Developing a negotiated management strategy rather than a prescriptive one can help the person with the condition feel more in control of their life, as well as enabling the health professional to recognise the individuality of the experience of chronic conditions. This notion of negotiation is not a novel one. Conway (1998), for example, has alluded to the importance of the "possibility of joint problem solving based on mutual respect" (p1314). A form of negotiated management can be used to the advantage of the health professional. For example, it is possible for health professionals to set boundaries within a negotiated management strategy.

### **Taking the context into account**

It is also clear, in keeping with other studies such as that of Chapple and Rogers (1999), that it is necessary to consider the whole person in their entire context in order to work with them in developing a management program. Contextual factors include things like significant others, the person's work place, the social context in which they live, lifestyle choices and individual priorities. Participants in our study were consciously weighing up managing the condition with its impact on their lives and making choices accordingly. It is important for health professionals to try to understand the context in which the person with the chronic condition is operating. It is also crucial to view them as an individual with a life that exists beyond the chronic condition and of which the chronic condition is only a part, rather than viewing the condition as the entire focus. Participants in our study wanted health professionals to

have the whole picture, not just a small part of it. There was a sense on the part of many participants that the management of their condition had become a routine of getting the medication their health professional said was required, as quickly as possible with little ongoing contact with the health professional concerned. This led to feelings of not being understood, or a sense of presumptions being made by the health professional – including that the health professional knew everything there was to know about the situation when in fact participants felt that they actually knew very little other than a set of symptoms.

### **Communication**

Communication needs to be a two-way process, with the health professional needing to take into account contextual factors and other forms of information that may be accessed by the person seeking treatment, as well as the person themselves attending to the information presented to them by the health professional. As mentioned earlier, the ability of the health professional to provide good information tailored to the need of the person concerned was paramount in participants' minds with respect to the appropriate management of their condition. However, equally important was the way in which that information was communicated – an often-overlooked dimension in information development. No matter how good the information was, if it was not conveyed effectively it inevitably lost its impact.

We have already discussed a further important dimension in the giving and receiving of information as a central construct of the management of a chronic condition – the need to share information on the part of both the person with the condition and the health professional. Dismissing the information that the person seeking treatment and help brings to the health professional can only lead to feelings of lack of worth. It will not stop people getting information from wherever they wish anyway. It may well be better to work with that information than to ignore it.

### **Managing risk perception**

As discussed above, it was clear from the study findings that management was considered by participants to be a very individual matter. This includes whether an individual chose to take what a health professional might term 'risks' with respect to their condition and the management thereof. Our analysis relating to participants' perceptions of risk provides an insight into the conscious decision making or weighing up process by people with chronic conditions. This weighing up process underpinned many individuals' choices as to whether or not to engage in what health professionals defined as risky behaviour. This finding strongly supports Heyman's

(1992) contention that it is too easy to dismiss behaviour such as smoking as simply ‘non-compliance’ when in fact there is often a rational judgement underpinning many of these actions. Our findings reveal an active rather than a passive ‘consumer’ in terms of participants weighing up and playing the odds.

In addition, our study found that differences in perception of risk, or at least the perception of the outcome of risk, related to perceptions of the immediacy of that risk. Thus if the risk seemed to be too far in the future, it was less likely to be of concern or seem real to the participants. Hence for the person with asthma referred to earlier, the risk associated with asthma would only seem real if she got emphysema. This supports Chapple and Rogers’ (1999) contention that the timing and stage of the condition affect the efficiency of self-care interventions. These findings demonstrate again the need for health professionals to work closely with the understandings individuals have about their condition, about ‘compliance’ and about risks associated with the condition. This includes making the risk seem real to the person concerned even if it does not seem immediate. By working with such understandings health professionals may be able to influence decision making pertaining to risk taking, and work with the individual once those choices have been made – even if they are not exactly those choices the health professional may have wished for. This is to highlight the importance of an approach to understanding risk that takes into account the “social and cultural contexts in which risk is understood and negotiated” (Lupton 1999, p24). Again it seems that what is needed is a more negotiated boundary setting approach to the management of chronic conditions, rather than prescriptive regimes that seem too deterministic and too removed from the reality of the individual with the chronic condition.

### **4.3 Multi-dimensional health research**

Finally in a different vein, our findings illustrate the importance of a multi-dimensional approach to understanding chronic conditions and their management. Fenton and Charsley (2000) argue that by mixing dimensions of analysis (in their case epidemiology and sociology), it is possible to refine and to complement purely quantitative approaches such as epidemiology. Our findings support their contention in that an interpretative study such as this, which forms part of an epidemiological population-based cohort study, enables us to interrogate the categories employed in the research such as risk and compliance. Fenton and Charsley support the mixing of qualitative and quantitative methods, noting that qualitative research demonstrates the “complexity and connectedness in the texture and meanings of social life which is difficult to reproduce in quantitative methodologies” (p404). Further, they note that

qualitative approaches can inform elements of the design of quantitative based studies, suggesting that “quantitative and epidemiological work should be informed by qualitative research and incorporate it as an allied and indispensable tool” (p404). The results herein will be incorporated into the epidemiological population-based cohort design in order to refine and improve the methods of data collection employed and the assumptions therein. As such this multi-dimensional and multi-method study will better mirror the reality of those with a chronic condition.

## References

- Bender, B., Milgrom, H. & Rand, C. 1997, 'Nonadherence in asthmatic patients: Is there a solution to the problem', *Annals of Allergy, Asthma and Immunology*, vol. 79, pp177-186.
- Burns, R. 1997, *Introduction to Research Methods*, Addison Wesley Longman, Melbourne.
- Chapple, A. & Rogers, A. 1999, 'Self-care' and its relevance to developing demand management strategies: A review of qualitative research', *Health and Social Care in the Community*, vol. 7, no.6, pp445-454.
- Charmaz, K. 1987, 'Struggling for a self: Identity levels of the chronically ill', *Research in the Sociology of Health Care*, vol. 6, pp283-321.
- Cheek, J. & Oster, C. 2000, *Experiences and Perceptions of Participating in the North West Adelaide Health Study*, Report by the Centre for Research into Nursing and Health Care, University of South Australia, August.
- Cleaver, G. & Pallourios, H. 1994, 'Diabetes mellitus: Experiencing a chronic illness', *South African Journal of Psychology*, vol. 24, no.4, pp175-183.
- Colagiuri, S., Colagiuri, R. & Ward, J. 1998, *National Diabetes Strategy and Implementation Plan*, Diabetes Australia, Canberra.
- Conway, A. 1998, 'Adherence and compliance in the management of asthma: 1', *British Journal of Nursing*, vol. 7, no.21, pp1313-1315.
- Ekman, I. & Segesten, K. 1995, 'Disputed power of medical control: The hidden message in the ritual of oral shift reports', *Journal of Advanced Nursing*, vol. 22, pp1006-1011.
- Fenton, S. & Charsley, K. 2000, 'Epidemiology and sociology as incommensurate games: Accounts from the study of health and ethnicity', *Health*, vol. 4, no.4, pp403-425.
- Forbes, M.A. 1999, 'Hope in the older adult with chronic illness: A comparison of two research methods in theory building', *Advances in Nursing Science*, vol. 22, no.2, pp74-87.
- Helman, C. 1991, 'Research in primary care: The qualitative approach', in *Primary Care Research: Traditional and Innovative Approaches*, Eds. PG. Norton, M. Stewart, F. Tudiver, M. J. Bass & E. V. Dunn, Sage Publications, London.
- Heyman, B. 1992, 'Introduction', in *Risk, Health and Health Care: A Qualitative Approach*, Ed. B. Heyman, Arnold, London.

- Hjelm, K., Nyberg, P., Isacson, A. & Apeqvist, J. 1999, 'Beliefs about health and illness essential for self-care practice: A comparison of migrant Yugoslavian and Swedish diabetic females', *Journal of Advanced Nursing*, vol. 30, no.5, pp1147-1159.
- Kaufman, S. 1988, 'Towards a phenomenology of boundaries in medicine: Chronic illness experience in the case of stroke', *Medical Anthropology Quarterly*, vol. 2, no.4, pp338-354.
- Kelly, M. & Dickinson, H. 1997, 'The narrative self in autobiographical accounts of illness', *Sociological Review*, vol. 45, no.2, pp254-278.
- Kyngas, H. & Hentinen, M. 1995, 'Meaning attached to compliance with self-care and conditions for compliance among young diabetics', *Journal of Advanced Nursing*, vol. 21, pp729-736.
- Leyshon, J. 1999, 'When good compliance equals good asthma control', *Community Nurse*, vol. 5, no.3, pp25-7.
- Lupton, D. 1999, *Risk*, Routledge, London.
- McWilliam, C., Stewart, M., Brown, J., Desai, K. & Coderre, P. 1996, 'Creating health with chronic illness', *Advances in Nursing Science*, vol. 18, no.3, pp1-15.
- Olsen, R. & Sutton, J. 1998, 'More hassles, more alone: Adolescents with diabetes and the role of formal and informal support', *Child: Care, Health and Development*, vol. 24, no.1, pp31-39.
- Paterson, B., Thorne, S., Crawford, J. & Tarko, M. 1999, 'Living with diabetes as a transformational experience', *Qualitative Health Research*, vol. 9, no.6, pp786-802.
- Patton, M.Q. 1990, *Qualitative Evaluation and Research Methods*, Sage Publications, Newbury Park.
- Rhodes, T., Stimson, G. & Quirk, A. 1996, 'Sex, drugs, intervention, and research: From the individual to the social', *Substance Use and Misuse*, vol. 31, no.3, pp375-407.
- Skilbeck, J., Mott, L., Page, H., Smith, D., Hjelmeland-Ahmedzai, S. & Clark, D. 1998, 'Palliative care in chronic obstructive airways disease: A needs assessment', *Palliative Medicine*, vol. 12, pp245-254.
- Slack, M. & Brooks, A. 1995, 'Medication management issues for adolescents with asthma', *American Journal of Health Systems Pharmacy*, vol. 52, no.13, pp1417-1421.
- South Australian Health Commission, 1990, *A Social Health Atlas of South Australia*. SAHC, Adelaide.

Sullivan, E. & Joseph, G. 1998, 'Struggling with behaviour changes: A special case for clients with diabetes', *Diabetes Educator*, vol. 24, no.1, pp72-77.

Taylor, S. & Bogdan, R. 1994, *Introduction to Qualitative Research Methods*, Wiley, New York.

van Es, S., le Coq, E., Brouwer, A., Mesters, I., Nagelkerke, A. & Colland, V. 1998, 'Adherence-related behaviour in adolescents with Asthma: Results from focus group interviews', *Journal of Asthma*, vol. 35, no.8, pp637-646.

Williams, C. 1999, 'Gender, adolescents and the management of diabetes', *Journal of Advanced Nursing*, vol. 30, no.5, pp1160-1166.



# APPENDICES

**Appendix 1:**  
**Information sheet for participants**

***“A Qualitative Investigation of the Experiences, Perceptions and Understandings of Chronically Ill People”: Part of the North West Adelaide Health Study***

Researchers from the North West Adelaide Health Study are interested in what it is like for people to live with chronic illness. We appreciate your participation in the clinical part of the study and we would like to give you the opportunity to be involved in an interview in which we are interested in *your* experiences and *your* views on what it is like for people who live with chronic illness. The interviews will form the qualitative part of the study.

The qualitative part of the project will investigate the experiences, perceptions and understandings of chronically ill people in order to provide a consumer perspective for research into chronic illness. In order to learn more about the perspectives of people who live with chronic illness, we will be conducting interviews with people from the North Western suburbs of Adelaide who have been diagnosed with a chronic illness.

The interviews can be done at any location that would suit you. It can be in your home, at the Queen Elizabeth Hospital or at any other location where you feel comfortable. The interviews will be quite informal and during the interview we would explore *your views* on what it is like to live with a chronic illness. The interviews are expected to last no longer than 1 hour and will be audiotaped and transcribed.

You **will not be identified** in any way in the interview transcripts. Anonymity and confidentiality will be maintained at all times. The information collected as part of this study will remain in a secure area at the Centre for Research into Nursing and Health Care, University of South Australia, for seven years.

Your participation in the study is voluntary. If you agree to take part in this study you are free to change your mind and withdraw at any time.

There will be \$20.00 available for your participation.

We look forward to hearing your views on this important topic and thank you in anticipation of your help with this study.

Questions?

If you would like more information about the study or have any concerns, you may wish to initially contact the Research Assistant – Candice Oster on (08) 8302 1532 or 0413 123 930. Telephone numbers for the Chief Investigators are listed at the bottom of the page should you wish to speak to them<sup>b</sup>. If you would like to speak to someone not directly involved in the study, you may contact Ms Linley Hartman (Chair of the University of South Australia Human Research Ethics Committee), tel (08) 8302 0327, fax (08) 8302 0512.

---

<sup>b</sup> Professor Julianne Cheek (08) 8302 2712, fax (08) 8302 2578. To contact Professor Richard Ruffin, Dr Patrick Phillips, Dr Brian Smith or Dr David Wilson please contact Ingerid, the study co-ordinator on 1800 635 352 or fax (08) 8222 6042.

**CONSENT FORM - TO PARTICIPATE IN AN INTERVIEW**

**Project: “A qualitative investigation of the experiences, perceptions and understandings of chronically ill people”**

**Researchers’ names:           Professor Julianne Cheek  
                                          Ms Candice Oster**

- I have read the Information Sheet, and the nature and the purpose of the research project have been explained to me. I understand and agree to take part in an interview.
- I understand that I may not directly benefit from taking part in the study.
- I understand that while information gained during the study may be published, I will not be identified and my identity will remain confidential.
- I understand that I can withdraw from the study at any stage and that this will not affect my status with the Queen Elizabeth Hospital or the University of South Australia now or in the future.
- I understand that I will be audiotaped during the interview and the tape transcribed.
- I understand that the tape will be stored in the Centre for Research into Nursing and Health Care and the only the researchers associated with this study will have access to the tape.
- I confirm that I am over 18 years of age.

**Name of Subject:** \_\_\_\_\_

**Signed:** \_\_\_\_\_

**Dated:** \_\_\_\_\_

I have explained the study to subject and consider that he/she understands what is involved.

**Researcher’s signature and date** \_\_\_\_\_

**Appendix 3:**  
**Interview Schedule**

***“A Qualitative Investigation of the Experiences, Perceptions  
and Understandings of Chronically Ill People”: Part of the  
North West Adelaide Health Study***

The interviews were conducted in an open-ended manner. The interviews were structured around a series of questions that were used as probes. Participants were informed that they were free to discuss any issues that may be pertinent to them. The ‘probe’ questions, which formed the interview schedule, were as follows:

- a) Can you tell me about the time when you were first diagnosed with [condition]?
- b) Do you remember your thoughts and feelings at the time?
- c) Did these thoughts and feelings change over time?
- d) If so, in what way?
- e) How would you describe your health at the moment?
- f) What has having [condition] meant to you and your life?
- g) Have you been told that there are things you need to do to manage your condition?
- h) If so, what are they?
- i) How do you find managing your condition? Is it easy? Is it difficult? Is it impossible?
- j) What are the things about managing your condition that make it easy, difficult or impossible?
- k) Would you describe yourself as a person who takes risks in regard to your condition?
- l) How would you define ‘risk’?
- m) How do you think health professionals (nurses, doctors, educators) could better assist you in managing your condition?
- n) Are there any other issues you would like to raise?

The interviewer informed the participants that they were free to refuse to answer any questions and to talk about any issues they wish to discuss. Issues of confidentiality were discussed prior to beginning the interviews.

**Appendix 4:**  
**North West Adelaide Study Team**

**CHIEF INVESTIGATORS**

Professor Richard Ruffin  
Department of Medicine  
The University of Adelaide

Dr Patrick Phillips  
Endocrine and Diabetes Service  
The Queen Elizabeth Hospital

Professor Julianne Cheek  
Division of Health Sciences  
University of South Australia

Assoc Professor David Wilson  
Department of Medicine  
The University of Adelaide

Ms Anne Taylor  
Centre for Population Studies in Epidemiology  
South Australian Department of Human Services

**ANALYSIS TEAM**

**Centre for Population Studies in Epidemiology  
- South Australian Department of Human  
Services**

Ms Eleonora Dal Grande  
Epidemiologist

Ms Catherine Chittleborough  
Epidemiologist

Ms Tiffany Gill  
Senior Epidemiologist

Ms Janet Grant  
Epidemiological Research Officer

**Division of Health Sciences, University of  
South Australia**

Ms Candice Oster  
Research Assistant

**CLINIC TEAM**

Ms Ingerid Meagher, Study Coordinator

Ms Else Jansen

Ms Sandy Pickering

Ms Megan Taylor

Ms Ruth Battersby

Ms Nardina Labiszewski

Ms Angelique Scardigno

Ms Mandy O'Grady

**RECRUITING STAFF**

Ms Jan Dibble

Ms Shirley Ogilvy

Ms Brenda Webb

Ms Kay Smith

**ADMINISTRATIVE SUPPORT**

Ms Jacqueline Hickling  
Project Officer  
Centre for Population Studies in Epidemiology  
South Australian Department of Human Services

## **Appendix 5: Reports**

1. Cheek J, Oster C. A qualitative investigation of the experiences, perceptions and understandings of people with a chronic condition: Part of the North West Adelaide Health Study. November 2000. University of South Australia. ISBN 0 7308 9193 3
2. Taylor A, Dal Grande E, Chittleborough C, Ruffin D, Wilson D, Phillips P. The North West Adelaide Health Study – Key biomedical findings, policy implications and research recommendations. May 2002. SA Department of Human Services. ISBN 0 7308 9189 5
3. Taylor A, Dal Grande E, Chittleborough C, Ruffin D, Wilson D, Phillips P. The North West Adelaide Health Study – Summary of key findings, policy implications and research recommendations. May 2002. SA Department of Human Services. ISBN 0 7308 9190 9
4. Wilson D, Appleton S, Taylor A, Dal Grande E, Chittleborough C, Ruffin D. The North West Adelaide Health Study – Risk factors and associated chronic diseases. June 2002. SA Department of Human Services. ISBN 0 7308 9191 7
5. Chittleborough C, Cheek J, Grant J, Phillips P, Taylor A. Education and information issues among people with diabetes. May 2002. SA Department of Human Services. ISBN 0 7308 9185 2

## **INTERNAL REPORTS**

- |          |                                                                                                                     |
|----------|---------------------------------------------------------------------------------------------------------------------|
| Report 1 | North West Adelaide Health Study – General overview of data collected in 2000                                       |
| Report 2 | Demographic characteristics of participants in the North West Adelaide Health Study compared with 1996 Census data  |
| Report3  | Community responses to the notion of taking part in the North West Adelaide Health Study                            |
| Report 4 | Community responses to the notion of having participated in the North West Adelaide Health Study                    |
| Report 5 | Interviews with subjects unwilling to participate in the North West Adelaide Health Study                           |
| Report 6 | Exit survey of people taking part in the North West Adelaide Health Study                                           |
| Report 7 | The North West Adelaide Health Study - Initial Results                                                              |
| Report 8 | Report to the Commonwealth Department of Health and Aged Care on the process of conducting a biomedical study in SA |

