MOTHERS, YOUNG PEOPLE AND CHRONIC ILLNESS:
MEANINGS, MANAGEMENT AND GENDERED IDENTITIES

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For my daughter, Rebecca.
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ABSTRACT

This thesis explores the ways in which gendered identities impact on both the meanings and the management of chronic illness during adolescence, using asthma and diabetes as exemplars. The study interviewed young people, and the parent most involved in helping the young person manage the chronic illness, who in almost all cases was the mother.

In order to examine how young people and mothers negotiate responsibility for self-management, young people aged 15-18 years were selected, as this is commonly recognised as a time of 'transition' towards independence. In depth interviews were conducted with 39 pairs of mothers and young people, and one father/daughter pair. The 40 young people interviewed consisted of ten girls and ten boys with asthma, and ten girls and ten boys with diabetes. A secondary 'contextualising' research strategy was also used, which included informal discussions with key informants such as nurse specialists and general practitioners, and clinic observations.

Ways of managing chronic illness during adolescence related to the specific effects that diabetes or asthma, and their respective treatments, had on gendered identities. Having a chronic illness did not appear to threaten the gendered identities of girls, and consequently they were more likely to incorporate their illness and its treatment into both their personal and social identities. In contrast, boys were very unlikely to incorporate asthma or diabetes into either their personal or social identities, because of the threats that chronic illness posed to their gendered identities. Many boys minimised their disease and any restrictions, but this was often only possible because of the 'invisible' help of mothers.

Mothers and health professionals had gendered expectations in terms of the dependency needs of young people, with teenage girls seen as more capable of independent self-management. This was reflected in the care that mothers gave, with teenage boys receiving more help and support from mothers, although this care was rarely recognised. The effect of caring on mothers was found to be extensive, and related to the gender of their child.

This study indicates that in the late 1990s, gendered notions of caring, dependence and responsibility are still very powerful and pervasive in both the private and public worlds of young people and their parents, impacting profoundly on the gendered ways in which young people manage chronic illness.
INTRODUCTION

Background to the study

My experience working as a nurse and health visitor for 20 years prior to undertaking an MSc made me increasingly interested in issues to do with gender and chronic illness, particularly in relation to self-help and self-care. My MSc dissertation explored the function of self-help groups from a sociological perspective, and my work as a health visitor had highlighted my interest in parents and children, so initially, I decided that my PhD would focus on young children with a chronic illness. However, preliminary reading of the literature indicated that there was little research on teenagers with chronic illness, and even less where parents were also interviewed. By exploring how young people lived with chronic illness I wanted to examine issues relating to the negotiation of independence and responsibility in terms of self-management, including whether the type of care parents gave, and autonomy in self-management, was affected by the child's gender.

As an important focus was how young people and parents negotiate responsibility for self-management, the narrow age range of 15-18 years was chosen, as this is commonly recognised to be a time when young people are in 'transition', moving towards independence. In attempting to categorise chronic illnesses in a sociological way, Conrad makes a distinction between 'lived-with illnesses' and other types of chronic illnesses, stating:

By lived-with illness I mean simply illness that a person must adapt to and learn to live with but which is (usually) not life-threatening....While these illnesses have different symptoms and manifestations, the problems that people must deal with and the strategies they develop may be quite similar (1987: 24).

I chose to interview young people with asthma and diabetes as they are both lived-with illnesses requiring high levels of self-management and self-care, and they have similar high levels of personal responsibility for 'juggling' treatment (Bytheway and Furth 1996).

Conrad concludes:

What I am recommending is that beyond focusing our research on "chronic illness" and specific disorders, we begin systematically to develop sociological conceptions of the illness experience. The crux of this analytic
strategy is to develop meaningful comparisons among illnesses on sociological grounds (1987: 27).

I hoped to achieve this by interviewing young people with these two different chronic illnesses. I decided to interview only the parent most involved in helping to manage the young person's illness, which in most cases I assumed would be the mother. However, the role that fathers play would also be explored through the interviews with mothers and young people.

Outline of the thesis

This thesis consists of four literature review chapters and one methodology chapter, followed by four analysis chapters. The final chapter concludes by drawing together the results of the study and making policy recommendations.

Chapter One examines asthma and diabetes from medical, social and gender perspectives, exploring in detail why these two chronic illnesses have been chosen as the focus for the study.

Chapter Two explores those aspects of gendered identities, including gendered embodiments, which may impact on ways of living with and managing chronic illness during adolescence. In particular, it focuses on the gendered ways in which young people learn to take responsibility for care, linking this to gendered notions of responsibility and dependence.

Chapter Three examines literature relating to the ways in which chronic illness is managed. The first section takes a historical perspective on the emergence of self-help, before examining how this has impacted on the current meanings of self-care and self-management. The second section looks at the meanings of 'compliance', particularly in relation to asthma and diabetes and the effects of age and gender. The last section explores the ways in which gendered identities impact on the management of chronic illness and stigma.

Chapter Four discusses how caring for children and young people comes to be seen as the responsibility of mothers, particularly when illness occurs. The chapter sets out and justifies the framework within which care by mothers will be explored, before examining the gendered expectations parents may have in terms of the ways in which their daughters and sons manage illness. It also explores the effect that care-giving can have on mothers when it is set within an 'ideology of competence' (Anderson and Elfert 1989).
Chapter Five, the methodology chapter, describes how the study was carried out, and discusses the limitations which constrained it. This chapter pays particular attention to the issue of gaining access to young people, and to conducting interviews with this age group.

Chapters Six and Seven are linked, exploring the caring that mothers perform in relation to young people with a chronic illness. The first of these chapters focuses on mothers' perceptions of gendered dependencies, and the ways in which these perceptions impact on how they care for daughters and sons in different ways. Chapter Seven explores in more detail the consequences for mothers of the autonomy/responsibility conflict (Silverman 1987b). Mothers are expected to encourage their teenage children to be autonomous in self-management, but they are still seen as responsible for any problems which arise. This chapter examines the gendered nature of the work mothers perform when encouraging independence, and the ways in which the gender of the child relates to the consequences that the autonomy/responsibility conflict can have for mothers.

Chapters Eight and Nine explore the impact of gender on ways of managing chronic illness during adolescence. Chapter Eight focuses on the gendered meanings of diabetes and asthma for young people, examining the extent to which the conditions are incorporated into their personal and social identities. In particular, it looks at the effects of the gendered nature of stigma in relation to asthma and diabetes. It also examines how gendered embodiments relate to feelings of control over the body, and consequently, to ways of managing illness. Chapter Nine focuses on the impact that gendered concepts of dependency and responsibility can have for young people in terms of chronic illness management. It examines the ways in which adherence to treatment can be affected by the gender of the young person, and the consequences that this can have for them.

Chapter Ten draws together the results of the study in a number of conceptual themes. It places the study in the context of the literature reviewed in the first four chapters, and evaluates its contribution to current literature. Finally, the chapter makes a number of health policy recommendations which arise as a result of this study.
Chapter One

ASTHMA AND DIABETES:
MEDICAL, SOCIAL AND GENDER PERSPECTIVES

This introductory chapter explains why asthma and diabetes have been chosen as the two chronic illnesses that may best help explore the issues at the centre of this research. These include firstly, the ways in which age interacts with the development of gendered identities during adolescence, and secondly, the gendered meanings of health and illness, and how these meanings relate to illness management.

It was felt that a study of young people with two chronic illnesses which both require high levels of self-management would be of most value in enabling gendered notions of dependence and responsibility to be explored. Self-management differs from most definitions of self-care in that it usually refers to a flexible, responsive regime predetermined by the health professional, which is then followed at home. Bytheway and Furth comment that, 'a particularly high level of responsibility for asthma treatment is carried by lay people', and that, 'diabetes mellitus is one of the few other potentially life-threatening conditions with a similar level of personal responsibility for 'juggling' treatment' (1996: 106). In addition, asthma and diabetes both incorporate specific aspects which relate to gendered identities.

In this chapter the biomedical and social aspects of diabetes and asthma will be discussed, together with gender issues which relate to these conditions. Adolescence is a key time in terms of health, with the overall pattern showing a gradual emergence of excess morbidity in females over this stage of the life-course. Many studies which explore the interrelation of gender and health examine the experiences of either women or men. The proposed research will compare the experiences of both young women and young men, because, in the words of Charmaz:

A more exacting look at the differential experience of men and women who suffer from serious chronic illnesses will deepen sociological and professional understandings of how they make sense of their lives. As the research in chronic illness grows, studying men and women comparatively in conjunction with marital, age, and social class statuses, in addition to the type of illness, can substantially refine sociological interpretations of the narratives of chronically ill people (1995: 287).
To place the study in context, this chapter begins with a brief discussion on the ways in which gender and age interact during adolescence to differentially affect the health of young women and young men.

1.1 Gender and the Health of Young People

In a detailed literature review examining sex differences in health during childhood and adolescence, Sweeting (1995) concludes that the overall pattern is of a gradual emergence of excess morbidity in females during this stage of the life-course. She found an excess of psychological disturbances and levels of chronic illness emerging amongst females in early to mid adolescence, in comparison to childhood, when males predominated.

There is evidence of a strong link between self-esteem and depression in adolescence (Allgood - Merten et al. 1990). Simmons et al. (1979) assessed sex differences in self-esteem changes amongst younger adolescents, and found the lowest levels in young women who had recently undergone multiple life changes, such as reaching puberty, changing schools, and starting opposite sex relationships. This contrasted with males who had higher self-esteem during early pubertal development. Similarly, in a large study of 3000 children aged 11 years, Sweeting and West (1995b) found that sex differences in self-esteem and self-reported health resembled those of adults, with boys significantly more likely to be happier about their looks and their weight. Boys were significantly less likely than girls to say that they avoided certain foods because they were slimming, or to be worried about weight gain or eating too much. The research found slimming and self-rated looks to be significantly associated with psychological well-being, with higher depression, anxiety and lower self-esteem occurring amongst dieters and those less satisfied with their looks, who were usually girls. Sweeting and West (1995b) concluded that this supports sociological and psychological literature which has attempted to explain the emergence of female psychological disturbances during adolescence as being caused in part by female dissatisfaction with body shape, in a context where high cultural value is placed on female thinness.

After reviewing the evidence in relation to health service utilisation, Sweeting (1995) concluded that sex differences in utilisation run parallel to sex differences in morbidity, with an excess of males amongst young children, reversing to an excess of females in early adolescence. However, she points out that early adolescence is probably the first time that young people are able to make independent decisions about health care use, as prior to that, responsibility is often taken by mothers. She therefore argues that the male excess in early
childhood could be due to the fact that mothers are more likely to take their sons to consult the doctor.

In relation to illness behaviour and beliefs, Sweeting (1995) concludes that during adolescence these become more sharply patterned by sex than for those of younger children. Radius et al. (1980) found a general tendency for more females than males to talk about health issues, with females reporting more concern when they were ill. In addition, the perceived future vulnerability of males to illness was not related to their past illness experiences, whereas females were much more likely to relate future vulnerability to their past experiences. Walker and Zeman (1992) found that although the parents of girls did not report more encouragement of illness behaviour than did parents of boys, girls reported more parental encouragement, leading Sweeting (1995) to postulate that either females perceive equivalent parental behaviours differently to males, or that males deny parental caretaking. It could also be argued that parents do encourage illness behaviour more in their daughters without being aware of it. Sweeting (1995) concludes that social learning is the key to differences in illness behaviour, with adolescents responding to societal pressures to conform to age and sex-appropriate behaviours. She argues that the excess in physical complaints emerging during adolescence in females may be directly related to the relative lowering of their psychological well-being during early adolescence. However, a review of the gender disparities in clinical decision making by the Council on Ethical and Judicial Affairs, American Medical Association, comments:

Perceiving men's use practices as normal and attributing overanxiousness to women's concerns about their health may be doing a great disservice to both sexes (1991: 561).

The authors highlight the fact that women's greater interest in health matters may partly contribute to women's lower mortality rates, whilst the tendency of men to ignore symptoms and under use health care may lead to more severe types of health problems.

This section has highlighted some of the key differences which emerge generally in terms of gender and health during adolescence. The rest of this chapter will now examine specific issues in relation to asthma and diabetes.
1.2 Asthma

1.2.1 Medical definition

Asthma is a chronic inflammatory respiratory disease that causes approximately 1500 deaths each year in England and Wales, with most asthma deaths occurring in those aged over 45 years (Lung and Asthma Information Agency 1997). A detailed definition of asthma was published in a consensus statement produced by the British Thoracic Society et al. (1993), and this definition remains valid for the recently updated guidelines published by the Guidelines Coordinating Committee (1997):

Asthma is a common and chronic inflammatory condition of the airways whose cause is not completely understood. As a result of inflammation the airways are hyper-responsive and they narrow easily in response to a wide range of stimuli. This may result in coughing, wheezing, chest tightness, and shortness of breath and these symptoms are often worse at night. Narrowing of the airways is usually reversible, but in some patients with chronic asthma the inflammation may lead to irreversible airflow obstruction. Characteristic pathological features include the presence in the airway of inflammatory cells, plasma exudation, oedema, smooth muscle hypertrophy, mucus plugging, and shedding of epithelium. These changes may be present even in patients with mild asthma when they have few symptoms (1993: S1).

1.2.2 Aetiology

Despite the fact that asthma is one of the major chronic health problems affecting people of all ages in all countries, the causes of asthma are as yet unclear, although they are probably multifactorial. There is evidence for asthma having an important genetic component, although this has not yet been fully characterised (Burney 1993). Anderson (1992) believes that while atopy increases the likelihood that a genetic predisposition to asthma will be expressed, the specific tendency to asthma is probably inherited independently. Artificial feeding, maternal smoking, manual social class and larger family size all increase the risk of wheezing in the first year of life (Burr et al. 1989), but appear to have less influence over its subsequent incidence (Anderson et al. 1986). The role of outdoor pollution is still unclear, but it is not believed to be a major factor in the increased prevalence of asthma (Wardlaw 1993). Anderson (1992) states that there is a clear relationship between respiratory infections in early life and the subsequent onset of asthma, probably because both conditions reflect either a general predisposition to chest illness, or continued exposure to an environmental agent. Common trigger factors include allergies such as feathers or fur; air temperature; infections; environmental agents; and stress.
Morbidity and Mortality

Asthma continues to be an important cause of respiratory morbidity and mortality, and is now the most common chronic childhood disease in Britain (OPCS 1998). It is generally agreed that the prevalence of asthma in both children and adolescents is increasing worldwide, and epidemics of deaths over the past 30 years have led to research on possible causes (Woolcock 1997). A recently published study by Campbell et al. (1997) which tracked deaths between 1983-1995 found asthma deaths in all but the oldest patients to be decreasing, after increasing in the ten years between 1974 and 1984. This suggests, according to Woolcock, that either the new asthmatic patients have mild disease or that treatment has improved. She believes the latter to be the case, although direct evidence for this is lacking. However, the ratio of preventive steroid versus bronchodilator medication also increased during this period. One of the key ways of attempting to improve treatment was the introduction of asthma self-management plans which involve the 'patient' in changing medication doses in response to worsening or improving symptoms.

Although Campbell et al. (1997) found downward trends in asthma mortality in Britain between 1983-95, they did not examine sex differences. There are contrasting differences in mortality rates according to sex in other countries. For example, in Japan, the death rate amongst young males is increasing (Woolcock 1997), whereas in Australia, asthma related deaths in children under 15 years of age occur mostly amongst boys, in comparison with over the age of 15 years, when most deaths occur in young women (Bureau of Statistics 1995).

In Britain the prevalence of asthma for all ages is around 5-7%, and in children it is estimated to be between 10-15%, although accurate figures are difficult to obtain (Asthma Training Centre and Royal College of General Practitioners 1993). Using a survey approach Strachan et al. (1994) were able to estimate more accurately the severity, prevalence and treatment of asthma in Britain for those aged 5-17 years. They found that in the previous year, 15% of children had wheezed, 2.2% had suffered more than 12 attacks, and 2.3% had experienced a speech limiting attack. They also found that the male predominance seen in pre-adolescent children had generally decreased by the later teenage years, with the change particularly marked for frequent and speech limiting attacks of wheezing.

Treatment

In general, medical treatment falls into two main categories of inhalers, and a combination of treatments is usually offered. 'Preventers' aim to stop asthmatic symptoms occurring by
treating the airway inflammation present in people with asthma. Many preventers are steroid based, and do not provide immediate relief from symptoms. In addition, they need to be taken regularly, often twice per day. 'Relievers', or bronchodilators, alleviate the symptoms of asthma by relaxing the muscles of the airways, and they are generally short acting, such as the commonly used salbutamol (ventolin) inhaler. Peak flow meters measure the degree of airway constriction, and may be recommended to be used regularly at home in conjunction with self-management plans.

1.2.5 General Practice and Asthma Clinics

In recent years there has been a notable move to shift asthma care from specialist hospital clinics into general practice. This could in part be related to the large cost to the NHS of hospital and pharmaceutical treatment for asthma, which was estimated at £404 million in 1990, or about £470 million at 1994 prices (Appleby 1994). Designated clinics were actively and financially encouraged through the General Practitioner Contract (Department of Health 1989), but there is little evidence at present to show whether they have had an influence on asthma morbidity and mortality rates. Much of the effort aimed at improving the care of children and adults with asthma in general practice concentrates specifically on patient and parent education, on the assumption that improving knowledge will improve compliance (Tettersell 1993). However, research shows that although people may demonstrate a significant improvement in their knowledge and understanding of asthma following education, this does not appear to affect their self-management behaviour or morbidity rates (Hilton et al. 1986; Jenkins et al. 1988). Many of the clinics are based on the use of self-management plans which have been promoted in guidelines produced by the British Thoracic Society et al.:

These recommendations promote greater use of inhaled anti-inflammatory drugs, even in patients with apparently mild asthma; objective monitoring of progress based on the patient’s own measurements of peak expiratory flow where possible; and greater participation of the patient or parents in the management of the condition (1993: S2).

Although there is some evidence that giving written self-management plans can reduce morbidity and health costs (Ignacio-Garcia and Gonzalez-Santos 1995), it is not clear exactly who would benefit from them, and what form they should take (Guidelines Coordinating Committee 1997). However, amongst the medical profession there is controversy about the effects of self-management plans on people with asthma, particularly with regard to the use of peak flow meters to measure peak expiratory flow. Butler and Wilkinson describe the detrimental effects for one of their patients, stating that:
..a vicious cycle is set up: a low mood results in poor peak flows, which confirm her debility to both herself and her family. The graphic downward trend in her record is a focus of anxiety for the whole household... for a small group of patients, monitoring of peak flow may contribute directly to their adoption of the sick role (1994: 1100).

1.2.6 Social Aspects of Asthma

There have been surprisingly few studies on the social impact of asthma. Using a standardised interview approach, Nocon and Booth (1990) examined the social impact of asthma on those aged between one and 84 years, and found that for many respondents, asthma had a profound adverse affect on their lives in areas such as schooling, social interaction, employment and physical activities. Asthma accounts for the greatest number of absences from school, and is implicated in poor academic work (Appleby 1994). Where control of asthma is poor in schoolchildren and young people, health professionals are advised that this may be due to 'poor supervision of treatment by parents' (Guidelines Coordinating Committee 1997: S5). Parents of asthmatic children also claim major effects on their lives, stating that asthma creates a 'constant worry', leaving them unable to relax (Quinn 1988). Hewett's study (1994) which explored the experiences and perceptions of 19 men with chronic severe asthma using a grounded theory approach, is one of the few studies using qualitative methodology. In contrast, he found that his respondents had learned to control their asthma to such an extent that it was no longer seen as a major problem in their lives. He also found that over half the sample did not consider themselves to be ill, and some did not consider asthma to be an illness.

The social construction of asthma has been well documented by Gabbay (1983), and specific aspects will be highlighted here because of their relevance to ways of managing asthma. In the 19th century most members of the medical profession assumed that asthma in women was a functional disorder, usually related to hysteria. However in the case of men with asthma, it was assumed that there was an organic cause, as men were deemed most unlikely to suffer from a nervous disease. In the 1930s a section of the medical community particularly emphasised the effect of emotions on asthma, asthma being one of the seven diseases originally labelled as psychosomatic. Until the mid 20th century it was accepted teaching that asthma was a nervous disease which was rarely fatal (Crockett 1993). This historical medical view of asthma may continue to influence the perception, treatment, and management of asthma by both doctors and patients, and Becker et al. state:

..the notion of having an emotionally-based illness serves to discredit asthma as a 'real' illness among health professionals and patients alike, contributes
to the sense of stigma that persons who have asthma experience, and impedes effective management (1993: 305).

1.2.7 Asthma and Gender

During in-depth interviews conducted with eight men and seven women, Elliot (1995) found that five of the women reported being told by their general practitioner (GP) that their asthma was due to stress, in contrast to none of the men. Parents' perceptions may also be affected by this emotionally based view of asthma. For example, Donnelly et al. (1987) found that 52% of parents believed their child used asthma to gain attention.

Amongst children the prevalence of asthma is higher in males until the mid-teens, when the sex ratio reverses, although the reasons for this are unclear (Gregg 1983). Women make up 75% of all adult hospital admissions for asthma in America, and the same pattern is found in the United Kingdom (Skobeloff et al. 1992). In a large American study of 33,269 patients admitted for asthma treatment, Skobeloff et al. (1992) found that under the age of 10 years, males were admitted nearly twice as often as age-identical females. In the 11-20 age group, admissions of males and females were nearly identical. Between 20 and 50 years, the female to male ratio was 3:1. After 30 years of age the length of stay was also slightly greater for females than males. The authors conclude that adult females are more severely affected by asthma, and raise the possibility that hormonal and biochemical differences related to sex may play a role in the pathophysiology of asthma.

In more recent research examining the relationship between phases of the menstrual cycle and asthma admissions, Skobeloff et al. (1996) found asthma presentations to be least frequent when serum oestradiol levels are at a sustained peak. They observed a four fold variation in asthma presentations during the perimenstrual interval (day 26 to day 4 of a 28 day menstrual cycle), when serum oestradiol levels decrease sharply after a prolonged peak. Skobeloff et al. conclude that monthly variations in serum oestradiol levels may influence the severity of asthma in adult females, and that: 'female sex may be a significant and independent risk factor for acute exacerbations of asthma' (1996:1840). These findings can be related to similar research on diabetes, which will be discussed later in this chapter (section 1.3.4).

1.3 Insulin-Dependent Diabetes Mellitus (IDDM)

Diabetes is a chronic metabolic disorder characterised by a raised blood glucose concentration, which is caused either by a deficiency of the hormone insulin, or by the
presence of factors opposing the action of insulin. Insulin is produced by the beta cells of the islets of Langerhans within the pancreas, its main metabolic function being to maintain blood glucose levels within the range of 3.5 - 8.0 mmol/dl. There are two main types of diabetes, the most common being non insulin-dependent diabetes, or 'Type 2' diabetes, which occurs mostly in people over the age of 40 years. Insulin is usually being produced, but in inadequate amounts, and blood glucose levels can be improved by diet, or diet and tablets.

Most cases of diabetes occurring in children and young people are of the insulin-dependent, or 'Type 1' category, and in this study, all of the young people have insulin-dependent diabetes. There is a severe lack of insulin, and daily insulin injections are necessary for survival. Population studies have shown a peak incidence occurring around the ages of 10-13 years, with two-thirds of people with insulin-dependent diabetes diagnosed before the age of 19 years (Laakso and Pyorala 1985). However recent research indicates an increase in the number of children aged under five years developing diabetes, although the cause of this is unknown (Gardner et al. 1997). It has been estimated that in the United Kingdom there are at least 20,000 people under the age of 20 with diabetes, with a prevalence of 0.14%, and a rising incidence (British Diabetic Association 1995). However, although it is the third most frequent severe chronic disease of childhood, IDDM is still a relatively rare condition (Sweeting and West 1995b). Variations in occurrence have been noted in relation to both the season of the year (Fleegler et al. 1979), and to geographical location (Ferreira et al. 1993).

Most studies have demonstrated a small excess of boys amongst newly diagnosed childhood IDDM cases, with the cumulative risk for boys highest in areas with the greatest incidence, such as Finland (Bingley and Gale 1989). Although the reasons for this are unclear, Green and Gale (1994) hypothesise that gender may modify the individual risk of developing IDDM by altering individual susceptibility, perhaps at particular stages of development and high growth velocity.

The aetiology of IDDM is unclear, although susceptibility to this type of diabetes is genetically determined. It is believed that one or more environmental triggers such as viruses may lead to the autoimmune destruction of the beta cells within the pancreas in those susceptible (Donovan and Morris 1995).
1.3.1 Morbidity and Mortality

In industrialised countries the long term prognosis is worse in early onset diabetes, with a higher risk of nephropathy (kidney damage) and increased relative mortality (Gardner et al. 1997). Although accurate figures are hard to obtain, it is believed that the situation is slowly improving with better treatment and monitoring (British Diabetic Association 1995). Chronic complications associated with diabetes include retinopathy, leading to impaired vision and in some cases blindness; nephropathy, which can cause renal failure; neuropathy, which can affect both the peripheral nerves and the autonomic nervous system; vascular complications causing coronary heart disease; peripheral vascular disease resulting in poor healing of wounds and circulation to the limbs; infections, including soft tissue infections of the extremities, osteomyelitis, urinary tract infections, candidiasis, and tuberculosis (Donovan and Morris 1995). Damage to the nervous or vascular systems may also cause impotence in men (Campbell and McCulloch 1979).

1.3.2 Treatment

Treatment of people with diabetes aims to reduce blood glucose levels to near normal, and in IDDM control is achieved through diet and insulin injections, and regular exercise is recommended. The diet currently recommended is a 'normal, healthy diet', low in sugar, fat and salt, and high in fibre. There are many different types of insulin available, which can be classified into either short, medium or long acting, and a combination of short and medium acting. The most commonly used regimes in young people are twice daily or four times daily insulin injections, with the latter seen as offering greater flexibility, and potentially, better control of blood glucose levels. It is recommended that blood glucose levels are checked regularly, and for young people this can mean up to four times per day. This is done by pricking a finger with a lancet, and placing a drop of blood on a reagent strip. The level is usually read by a blood glucose meter. An additional test usually performed at specialist clinics is the measurement in the blood of glycated haemoglobin (HbA1), which reflects the average blood glucose level over the previous six to eight weeks.

Currently there is controversy amongst diabetologists over the extent to which treatment should aim for 'perfect' glycaemic control (British Diabetic Association 1995). The much publicised Diabetes Control and Complications Trial (1993) concluded that intensified control reduced retinopathy risk by half or more, and also reduced nephropathy and neuropathy risks. However, the drawbacks of this intensive intervention included a threefold risk of increased severe hypoglycaemic episodes, when the blood glucose level falls too low, often resulting in a coma. It is thought that there may be a link between loss
of IQ and multiple severe hypoglycaemic episodes (McKee 1995). Amongst the groups targeted for tight control are children and young people, who have many years in which to develop complications.

At present most people, particularly children and young people with IDDM, are treated in specialist hospital clinics, although this may change with the increased emphasis on care in the community (British Diabetic Association 1995). As with asthma, education is seen by health professionals as crucial for the person with diabetes:

The diabetic patient must be his own doctor, dietician and laboratory technician. Hence, education is the single most important aspect of treatment (Diabetes Control and Complications Trial 1993: 38).

1.3.3 Social Aspects of Diabetes

Before the early 1960s people with diabetes did not generally participate in the negotiation of self-management. Doctors tended to prescribe the appropriate insulin dose and hand over a diet sheet, giving limited information to patients (Wikblad 1991). However children and adults with diabetes are now expected to manage complicated regimes at home, fitting them into their daily lives. People with diabetes have to balance their food intake with their level of physical activity and the amount of insulin injected, and injections must be coupled with meals. They are also expected to monitor their blood glucose levels. Lifestyles often have to be changed in order to accommodate these regimes, leading Armstrong to state that:

..the intricate, complex and time consuming actions necessary to ensure that food, exercise and insulin are in the right proportions to result in glucose homeostasis are among the most demanding of any chronic illness (1987: 563).

Schafer et al. (1983) believe that with the wide range of responsibilities given to children and adults with diabetes, it is hardly surprising that people only selectively comply with various aspects of the treatment regime. Peyrot et al. (1987) contend that the interplay between personal and professional knowledge and the implications for how one chooses to live with diabetes are complex. On the one hand, medical knowledge maintains that even a moderate degree of undertreatment, resulting in higher blood glucose levels, increases the risk of long term complications. However, from the patient’s viewpoint, moderate undertreatment is less likely to produce immediate unwelcome symptoms such as hypoglycaemic attacks, and is easier to implement with fewer immediate sacrifices and
restrictions. This may cause particular problems for the negotiation of self-management between young people with diabetes and their parents. As Goldstein and Hoeper state:

..the child with diabetes, who under parental supervision had been following the prescribed medical care regime to the letter, refuses to follow the rules at puberty...the parents, who had worked hard to control the diabetes, suddenly find their efforts rebuffed (1987: 1).

In relation to young people, Kyngas and Hentinen (1995) state that the move to independence may be restricted, since the young person is not usually entrusted with total responsibility for self-management. At this stage in their lives young people are often involved in peer group activities, and the lack of spontaneity associated with the diabetic regime may lead to parts of the regime being abandoned, causing conflict with parents (Kelleher 1988). Problems related to compliance are frequently noted in young people with diabetes (Rapoff and Barnad 1991), with diet proving to be the most difficult aspect of self-management (Reynolds et al. 1990). From the literature, it appears that the second most difficult aspect for young people to accept are the regular home blood tests required, with insulin injections being the easiest part to implement (Karloy and Bay 1990).

When exploring the impact of marriage and having children on young adults with IDDM, Ahlfield et al. (1985) found the daily lives of young adults to be affected in various ways, including interactions with members of the opposite sex, choice of and compatibility with their marital partners, harmony within the marital relationship, and the decision on whether or not to have children. This led them to conclude that these issues should be discussed with young people with diabetes, as they could be experiencing initial relationship difficulties.

In addition to the general problems associated with having a chronic illness, there are specific issues related to IDDM. Robinson (1993) states that in the United Kingdom unemployment and difficulty in getting a job are particular problems for young people with diabetes. People with IDDM also face many employment restrictions, in that they are not usually permitted to work in situations where sudden hypoglycaemic attacks could endanger either themselves or others. Jobs either excluded or requiring regular medical assessments include the Armed forces; police; navy; fire brigade; pilots and divers; taxi, HGV and train drivers; working at heights; and controlling heavy machinery. Kyngas and Hentinen (1995) found one of the major causes for non-compliance in young people with IDDM who had previously been compliant was disappointment over occupational expectations.
In the case of diabetes, unlike asthma, there is no question that it is not a 'real' illness. However, in the 1930s, doctors of the newly formed psychosomatic movement became interested in the effect of emotional factors on the course of diabetes, specifically in patients who were 'difficult' (Tattersall 1997). By the 1950s it was proposed that there might be two distinct groups of 'difficult' patients. Firstly, those whose unstable diabetes could be cured by adjusting insulin, diet and exercise, and secondly, those whose unstable diabetes had an emotional origin. However, in his recent review of brittle diabetes Tattersall (1997) noted that twenty years ago, in 1977, he suggested that the definition of brittle diabetes should be a patient whose life was: 'constantly disrupted by episodes of hypo or hyperglycaemia, whatever their cause' (1997: 99). During the 1980s, British and American doctors investigated many patients with brittle diabetes using new biochemical methods, in an attempt to uncover what were perceived to be biochemical causes, such as defective insulin absorption. However, in his review Tattersall states: 'Most of these patients were young overweight women and the eventual conclusion was that in most cases the instability was self-induced' (1997: 99).

Tattersall (1997) then examines the history of the link between eating disorders and brittle diabetes, which was first made in 1980 (Fairburn and Steel 1980). Since then, he states, research has indicated that:

..a high proportion of young women with IDDM underdose themselves with insulin to lose weight or to maintain a stable weight while going on eating binges....It is possible that our (well intentioned) emphasis on diet as one aim of the treatment of IDDM has actually contributed to the problem of eating disorders among our patients (1997: 106).

Studies cited include those by Stancin et al. (1989), who found that 39% of 59 women with IDDM aged 18-30 years reported underdosing with insulin in order to lose weight, and 12% met the criteria for bulimia. In a review of the literature on eating disorders and IDDM, Rodin and Daneman (1992) found eating disorders to be relatively common amongst young women with IDDM, contributing to both short and long term complications. They found omission or reduction of the insulin dose to be an extremely common method of weight control in young women. Rodin and Daneman argue that two specific factors related to the diabetic regime, namely the required dietary restraint and the close monitoring of weight, impact more on young women than young men. In contrast, Orr et al. (1986) found a small group of teenagers, again, mainly girls, who took extra insulin secretively, which they concluded could be one symptom of serious underlying psychiatric dysfunction in adolescents with insulin-dependent diabetes.
Kent et al. (1994) emphasise the importance of brittle diabetes, in that although the people diagnosed with it, who are almost all young women, tend to become more stable over time, long term follow up indicates that they have a higher risk of death, more microvascular and pregnancy complications, and a poorer quality of life. Kent et al. (1994) conclude that although it has been observed by clinicians (e.g. Tattersall 1985) that time and patience are the major principles of brittle diabetes management, their study indicates that during this wait for resolution, complications and even death may occur. In a commentary on Kent et al.'s (1994) paper, Steele states:

> In clinical practice it is clear that almost all these patients are manipulating both their diabetes and the people around them. The lengths to which they can go are extraordinary...They seek and gain attention. They may focus on a particular doctor. I have been asked by assorted handsome young registrars, when they move to new posts, if I would be kind enough to take over the care of a "very difficult girl"; not uncommonly the problem miraculously solves itself without any direct intervention...Even now, many clinicians are unwilling to confront the problem. There is a natural reluctance to believe that patients would deliberately cheat their doctors and, after all, "she is such a nice girl she would never do anything like that" (1994: 765).

This reference has been included to illustrate some of the rather pejorative language that can be found in the medical literature in relation to brittle diabetes. Girls have been described as 'manipulative', 'cheating', 'attention seeking', 'malingering', 'faking', and in terms of families, Tattersall states that: 'It has repeatedly been observed that patients with brittle diabetes come from dysfunctional families....' (1997: 107).

In contrast, Peyrot et al. (1987) suggest that being classified as having 'brittle diabetes' serves to remove the blame for poor control from the person with diabetes, who is then not held responsible for the outcomes attributed to their 'disease'. They also believe that this classification can mitigate self-blame and resolve the conflicts of diabetic people with health professionals and family members. In their research Callaghan and Williams (1994) found that several of their interviewees explained their poor control by blaming the very nature of the diabetes itself, referring to their diabetes as 'brittle'.

Hypoglycaemic attacks are also associated with menstruation, with 30% of women reporting difficulties controlling their blood sugar level for up to a week prior to menstruation (Walsh 1983). The fact that exercise is thought to have a beneficial effect on IDDM by improving insulin action (Johnson 1992) may also impact differentially on young men and women, as exercise is more popular amongst young men (Miller et al. 1993).
Pond et al. (1996) have shown that diabetic control as measured by HbA1 blood results is poorest during the adolescent years with an equal decline in both sexes. The authors state that although the hormonal changes of puberty are sometimes blamed for the decline in control, it would be expected that the deterioration would be seen earlier in girls, and their research found the rise in HbA1 to be coincident between the sexes. They also found that the quality of control was worse in women than men at all ages from the mid-teens onwards, and the authors suggest that this may be because women often have to cope with both their diabetes and the care of their families.

In an earlier study, Hentinen and Kyngas (1992) explored the relationship between compliance and control in 47 young people aged 15-17 years with diabetes, using a questionnaire approach. They found small differences in the self-assessments of compliance between girls (n=15) and boys (n=32). A high degree of compliance was reported by 33% of both girls and boys, 33% of girls and 50% of boys reported an average degree of compliance, and 33% of girls and 16% of boys reported a low degree of compliance. However, when this was compared with diabetes control as measured on the basis of HbA1 values, only 20% of the girls showed 'acceptable' HbA1 values, compared to over 50% of the boys. HbA1 values were 'very poor' in 27% of the girls, and only 3% of the boys, but this gender difference was not commented on. In addition, nine young people who showed poor compliance and diabetes control declined to participate in the study, but their gender is not reported.

1.4 Conclusions

This chapter has outlined the reasons why these two contrasting diseases have been chosen to highlight the variety of strategies used by young people to manage chronic illness. The medical treatment of both asthma and diabetes relies heavily on self-management, and this important issue will be discussed at greater length in future chapters. The proposed research aims to explore the ways in which age and gender affect the negotiation of self-management, and the management of chronic illness. Both asthma and diabetes have a specific treatment regime but there is arguably more leeway in the management of asthma, in that it may be possible to be more flexible with treatment in the short term at least. In contrast, ketoacidosis due to lack of insulin in diabetes can lead to coma and death within 24-48 hours if untreated. With diabetes there is more emphasis on the prevention of long term complications such as blindness and renal failure.

There are also epidemiological differences between diabetes and asthma. Amongst children, the prevalence of asthma is higher in males until the mid-teens when the sex ratio
reverses, but the reasons for this are unclear (Gregg 1983). In contrast, there is evidence of a slightly higher incidence of diabetes amongst males during adolescence. However, in terms of morbidity and control of both diseases it appears that adolescence is a critical time when control worsens, particularly for young women. This fits in with the general trend of health during adolescence, when there is a gradual emergence of excess morbidity in females over this stage of the life-course. There is debate as to whether biochemical, hormonal or social factors - or a combination of all three - cause this reversal of childhood patterns in asthma and diabetes, which then continues throughout adult life. This research aims to explore some of the social factors which may impact on gendered ways of managing chronic illness during adolescence.
Chapter Two

TRANSITIONS TO GENDERED IDENTITIES

This chapter will focus on the development of particular aspects of gendered identities which may impact on ways of living with and managing chronic illness during adolescence. These include the gendered meanings of responsibility and dependence, and gendered embodiments and power relations. The chapter will also examine various influences on the ways in which the concepts of transition and adolescence have been constructed, and how these impact on our understandings and expectations of young people today. It is important to see adolescence not as a finite age set apart, but as an age affected by what has been before, and what is to come. Research relating to younger children and to adults will therefore be included where relevant.

The approach taken in this thesis will be based on that of West and Zimmerman (1987) who talk in terms of 'doing gender'. They state that this involves the interaction of socially guided perceptual, micropolitical and interactional activities, causing particular patterns of behaviour to be seen as 'feminine' or 'masculine'. Gender is not viewed as the property of individuals, but as an emergent feature of social situations that both arises from and legitimates gender inequality. However, it is also recognised that everyday behaviour is enacted within the social constraints and opportunities available to individuals, depending on their locations within social systems (Howard and Hollander 1997).

This chapter will look firstly at the ways in which age, adolescence and transition can be seen as socially constructed, and how this has influenced research approaches to young people. It then explores the gendered meanings of responsibility and dependence. Lastly, it examines the development of gendered embodiments and embodied power relations, and the ways in which these relate to the formation of gendered identities.

2.1 The Social Construction of Adolescence and Transition

Youth is defined by Jones and Wallace as: 'a process of definition and redefinition, a negotiation between young people and their families, their peers and the institutions of wider society' (1992: 4). In highlighting some of the problems in defining youth, Jones and Wallace (1992) state that whilst technically, adolescence can be defined as the period between puberty and the age of majority, theoretically it is seen by many as the stage of
transition from dependent childhood to independent adulthood. Other sociologists have suggested various criteria as markers for entry into adulthood in Britain including:

- Physical maturity, via puberty
- leaving full-time education
- entering employment and earning a wage
- leaving the parental home
- setting up an independent home
- family formation, via sexual partnerships and parenthood
- independence as a consumer
- legal recognition of citizenship

(Pilcher 1995: 63)

However, Jones and Wallace (1992) argue that there are many problems with these markers because some are defined according to physical development, some according to economic and social development, and others according to legal status. To clarify these issues it may be helpful to distinguish between the three major meanings of age - chronological age, social age and physiological age - to help illustrate how age itself, one of the key factors on which the concept of adolescence is based, is both socially structured and gendered (Arber and Ginn 1995).

2.1.1 Age as a Social Construct

In Western societies chronological age refers to numerical age in years, itself a social construct (Fortes 1984). The significance of chronological age relates to its importance in Western cultures, where it is used: 'to prohibit, compel or permit individuals to participate in certain activities, according to their year of birth' (Pilcher 1995: 3). In general, until the age of about 16 years the lives of children are extensively controlled and regulated in British society, leading Pilcher to state that: 'there is an organised separation of the world of children from that of adults' (1995: 2).

Social age is also socially constructed, relating to: 'age norms as to appropriate attitudes and behaviour, subjective perceptions and ascribed age' (Arber and Ginn 1995: 7). In discussing the Western experience of dependency as one of both loss of self-esteem and stigmatisation, Hockey and James (1993) relate it to the historical emergence of sets of ideas about individualism and childhood. They believe the central contradiction splitting the Western ideology of childhood to be dependency, which defines the child as 'different, innocent and vulnerable'. However, during the life-course of individuals in Western cultures, they state that this dependency must somehow be discarded in favour of the
'individualistic and knowledgeable' independence which is seen as the mark of adulthood. Although social ageing relates to life-course transitions, both the timing and sequencing of these transitions can vary for women and men, leading Ginn and Arber (1995) to conclude that social ageing is gendered. For example, in relation to the concept of independence, Daykin (1993) found the lives of young women to be more constrained than young men by both the structures of the labour market and by expectations within the family, and this will be discussed in more detail in Section 2.2.

Physiological age does have a biological reality, being a progressive, dynamic process. However, Arber and Ginn argue that: 'both the speed and timing of these physiological changes varies according to position in the social structure, especially gender and class' (1995: 10). For example, it is recognised that physiologically, girls often mature at an earlier age than boys, and it may be that they are treated differently because of this.

2.1.2 Adolescence as a Social Construct

Alderson (1996) states that the idea of a 'transitional' period of adolescence between childhood and adulthood is a recent one. Until the beginning of this century, she states that children were in many ways treated as adults once they were old enough to work. Although there was a social class difference in the length of time that childhood extended over, there was no real concept of a 'transitional' stage. Alderson describes what she sees as some of the key movements in the development of the 'story' of adolescence as follows:

- the state school systems from the 1880s, which took many street-wise children away from employment and adult society;
- the demands of modern industrial society for workers who have had years of schooling;
- the gradual rise in the school leaving age;
- increase in national concern about managing the health of young people and their future reproductive health;
- rising unemployment rates among adults, who prefer young people to be at college or in 'training schemes' and not competing for real jobs;
- the growth of commercially driven youth cultures;
- recent reductions in benefits for people under 25, and housing shortages which delay their move away from the parental home (1996: 10).

However, Alderson (1996) argues that these are all broadly social and political factors which indicate more about the ways in which adults manage society than about the abilities of young people. She also highlights the major and continuing influence of the psychologist Stanley Hall's book, 'Adolescence', published in 1904, and she claims that many of the
current concerns about adolescence as a transitional time with particular problems can be traced back to earlier works such as this. These psychological conceptualisations of youth have been influential in moulding both lay and medical attitudes towards young people. Psychological theories tend to see adolescence as a scheduled passage to adulthood which is embedded in biological events, and characterised by the tasks of individual development (Brannen et al. 1994). Erikson's (1968) view of adolescence as a period of emotional turmoil and conflict with parents and other adults has been particularly influential, although Apter (1990) criticises it for being based on work with very distressed adolescents.

The conflict has been described as functional and necessary for the establishment of independence (Coleman 1990), but this viewpoint has been criticised for its lack of attention to gender. Gilligan (1982) argues that the whole notion of individuation and movement towards autonomy has been based on a male model of development. Following her qualitative research with girls, she argues that the female model of development stresses the continuing importance of attachment. Apter's (1990) research on mothers and daughters supported Gilligan's (1982) work, leading her to state that:

..most mothers I spoke to expressed surprise that their daughter's adolescence was not as tumultuous, difficult or alienating as they had been led to expect (1990: 59).

Lees (1993) also argues that the very concept of adolescence is a masculine construct, with boys and men taken as the standard in youth research. This leads to maturity being defined as the development of autonomy rather than responsibility for others, or interdependence. Further, she believes that girls cannot behave as 'typical' adolescents, that is, recklessly or selfishly rebellious, without infringing what are seen as the attributes of femininity. Daykin states that the transition to adult status is more complicated for young women, because of certain contradictions which impact on them:

The discourse of femininity itself creates expectations of passivity and submissiveness which continually undermine attempts to obtain the independence and autonomy associated with adulthood (1993: 98).

Supporting these views, studies which look at gender role identity find that masculinity as opposed to femininity predict self-esteem in adolescents, although in younger children both masculine and feminine traits are associated with self-esteem (Allgood-Merten and Stockard 1991). This leads Allgood-Merten and Stockard to conclude that:
...coming of age for young women in post-industrial society brings with it a double-bind - a marked devaluation of that which is female, yet being female - which makes it very difficult to feel good about oneself (1991: 137).

Alderson criticises the whole concept of adolescence stating that: 'The story bears little relation to reality, except when it becomes a self-fulfilling prophecy of immaturity' (1996: 21). This view relates to the fact that over the past decade the study of children and childhood has flourished, and within the disciplines of sociology and social anthropology there has been a growing realisation that previous understandings of childhood were constructed through the viewpoint of adults. Research which sees children and young people as social actors in their own right, rather than being passively socialised and dependent on adults has revealed how much children have in common with adults. Alderson draws on this new research to refute the myth that there are clear differences between the child, the adolescent and the adult, asking:

Why do we label adult expressions of emotion or selfishness as 'the child within us' or 'being adolescent' instead of recognising that at every age we have mixed abilities: rational and impulsive, wise and foolish, selfish and altruistic? (1996: 14).

She warns against binary ways of thinking that tend to oversimplify complex realities, which can mean that similarities are discounted and superior qualities are ascribed to one group, such as adults being seen as wise, mature and competent in relation to children and young people.

Other research highlights the cultural specificity of adolescence. For example, Brannen et al. (1994) found that many parents in their study who came from Asian and Middle Eastern countries did not perceive adolescence as a transition to independence leading to separation from the family. Instead, transition to adulthood was seen as entailing increasing responsibility towards others, particularly within the household.

2.1.3 Transition as a Social Construct

Alderson (1996) states that the concept of transition can also be seen as a social construct, and argues that change over any ten year period is inevitable. She believes that the very existence of the concepts of transition and adolescence can lead to young people who are fully developed both physically and intellectually being treated as more like dependent young children than adults. Brannen (1995) agrees, stating that the current sociological concept addressing the status of children in families is that of dependence, with the concept of independence only seen as applicable when children leave home and become economically
self-sufficient. Brannen (1995) believes dependence to have connotations of passivity, seeing the implied dualism between the concepts as problematic. She argues that the concept of interdependence may better conceptualise children's relationships with family members.

In examining this key concept of transition between dependence and independence, Hockey and James (1993) state that those who are not perceived as fully adult occupy an ambiguous position on the margins of the adult world. They believe adults to have a power and decision-making responsibility which is denied to children, and in each relationship therefore, power is unevenly balanced. Hockey and James (1993) also believe that dependency is not an intrinsic quality, but a social relationship based upon the exercise of power, which is tied in to the specific social, political and economic relationships which affect the life-course of all individuals.

This section has established that the notions of adolescence and transition are problematic, highlighting the ways in which the social constructions of adolescence and transition have influenced the thinking around this age group. The importance of concepts such as independence, dependence and power for young people have been highlighted. Although there was some discussion of adolescence as a gendered concept, much of the published research does not specifically examine this aspect.

2.1.4 Research With Young People

Brannen and O'Brien (1996) observe that children and young people have often been neglected in terms of both family research and illness research. They believe this to be due to researchers' assumptions about the appropriateness of including children in research because of concerns about their competence, and also to anxieties about the protection of children. Brannen and O'Brien (1996) also highlight the converse problem of underplaying parental perspectives and contexts. In relation to what she sees as the current prolonged parental responsibility for young people, Brannen states that: 'despite the importance policy makers place on parents as agents of socialization and social control, there is virtually no support for them' (1996: 115). She links this to the failure of academic research to situate young people within families. By interviewing both young people and their main 'care-giving' parent, the proposed research aims to overcome these problems, by giving equal weight to both perspectives.

The period from the post-war years up to the 1980s has been characterised as moving from the 'celebration' to the 'marginalisation' of youth (Coffield 1987). Griffin (1993) states that during the 1980s British and American research on young people was dominated
by: 'a series of moral panics and constructed crises over young people and issues related to 'youth' such as 'teenage pregnancy' and 'youth unemployment' (1993: 199). She notes a key area of debate within radical youth research to be the tension between the construction of young people as passive victims of oppression, or as active social agents who are capable of both resisting and altering the conditions of oppression. Griffin (1993) also criticises research which takes a victim-blaming stance by representing young people as 'deviant' or otherwise inadequate, and with a tendency to psychologise inequalities, which serves to obscure the structural relations of domination. Oakley et al. (1992) see a similarity between the ideological problem of youth today and the 'woman problem' of the 19th century, in that both are minority groups about which society has ambivalent attitudes, including protection and fear:

On the one hand, young people are seen as essentially childlike and in need of protection and control; on the other, the potential power of young people to act against adult norms is feared for its socially disruptive effects (1992: 76).

In relation to research on the health of young people, much of it emerges from within a historical problematisation of the teenage years by a range of professional groups including health, welfare and education workers (Oakley et al. 1992). Hill and Fortenberry (1992) believe that adolescence is seen as the inevitable 'risk' factor for many widespread problems such as pregnancy, drug abuse and suicide, rather than them being seen as products of complex interactions of individual biology, personality, cultural preference, and political expediency. They argue that adolescence has been created as a developmental period defined by its problems, and 'medicalised' into a condition which is seen as inherently pathological. This can be illustrated by an editorial in 'The Lancet' entitled 'Maturing Dangers', which begins: 'Teenagers in 1995 live dangerously' (Editorial 1995: 997). In relation to young people and health, Harding states:

..remarkably few studies of adolescent health beliefs have considered in any detail the adolescents themselves, but instead have simply acknowledged them as a group given to taking risks with their health...little is known of the social mechanisms which develop this group's responsibility for taking chances with their health (1989: 30).

Jones and Wallace (1992) believe that this ambivalent attitude may be one reason for the lack of research on young people and their parents. In addition, they argue that there are three problems which the sociology of youth has failed to solve. Firstly, there is a problem in how to locate young people in society, whether as individuals, as a social group or as family members. Secondly, they believe that there is also a difficulty in seeing young
people as whole individuals, in whom social roles and relationships are integrated. Thirdly, they identify a difficulty in coping theoretically and methodologically with the fact that young people are in process of transition within a changing society. Because of these problems, Jones and Wallace believe new theoretical frameworks need to be developed for studies in the sociology of youth, stating:

"a coherent theory is needed to help us understand the intra-family and wider social processes which shape youth and the transitions which comprise this part of the life course, but the theory should also allow us to explore how ideologies of youth develop and are imposed through state policies. This means that we need to understand historical change as well as individual life-course transitions (1992: 18)."

Jones and Wallace (1992) have criticised the life-course approach for its focus on individuals which they feel may lessen the recognition of structural inequalities, although they consider it to be a valuable approach for the study of age and transitions within historical contexts. Bury goes further, stating: 'although a life-course perspective constitutes a useful organising framework for social research, it too often remains vague at a theoretical level' (1995: 28). He advocates a more focused approach on the links between the macro and micro levels of analysis, stressing the need for a particular emphasis on the exercise of power and the counter effects that social action may have on these hierarchies of analysis. Bury (1995) also draws attention to the ways in which the experience of gender and age lead to differences in power relations, thus affecting the ability of people to make transitions. This is supported by Brannen and O'Brien (1996), who state that although children may differ greatly in the material and cultural resources they have access to, children's gender is likely to be central to their ways of negotiating the complexities of life.

The purpose of this section has been to highlight the ways in which the social constructions of adolescence and transition have influenced both the thinking and the research on young people. The proposed research will attempt to incorporate these ideas into a theoretical framework using a life-course approach, thus enabling young people with a chronic illness to be placed within the family, yet taking account of the wider social, structural and historical processes impacting on them. The research aims to promote the view of young people as key actors, and will look critically at the effects that the concepts of transition and adolescence have on their lives, particularly in relation to the management of chronic illness. A key focus of the proposed research will be to explore how gender interacts with the social constructions of adolescence and transition. This will include examining the gendered meanings of dependence, independence, and the exercise of power, and these issues will now be explored.
2.2 The Gendered Meanings of Responsibility and Dependence

This section will firstly explore the gendered meanings that responsibility can have, focusing particularly on how young people learn to be responsible for care. It will then highlight the gendered meanings that dependence can have, before discussing autonomy.

2.2.1 Responsibility for Care

How young people learn to care is difficult to assess, as much of the 'learning' and 'teaching' is invisible, occurring in many different areas of life. This section will highlight some of the more important ways in which gendered aspects of caring may be learned.

Much research highlights the ways in which family life helps construct gender identities through socialisation, thus reproducing gender inequalities. Griffin (1986) found girls to be more restricted than boys by familial authority, with more domestic responsibilities. Studies of gender differences amongst children and adults in relation to household tasks show that women do the most, followed by girls, then boys, and lastly, men (Frones et al. 1992). Brannen (1995) draws on the work of Goodnow and Delaney (1989) to make the distinction between responsibility for clearing up after one's self, which they call self-care work or self-maintenance, and responsibility for clearing up after others, or family-care work. A key distinction between these two types of work was that when compared to self-care work, family-care work allowed for the possibility of passing jobs on to others. Gender differences were found in terms of family-care work, with girls significantly more likely to perform it than boys, although there were no pronounced differences in relation to self-care work. Brannen (1995) concludes that this may help explain the persistent gender differences in adulthood in relation to the domestic division of labour. She suggests that whilst some parents emphasise the importance of self-care work to their children, this approach may turn out to be a poor way of preparing boys to take on domestic responsibility voluntarily in adulthood. When commenting on the results of the Young Person's Social Attitudes Survey (Jowell et al. 1995), Oakley (1996) also found that significant gender differences between young women and men existed. Household tasks were gendered, with looking after sick family members being one of the roles of women that young men were especially reluctant to take on.

Linked to the idea of learning to care for oneself and others is the notion of responsibility. When researching accident stories, Green and Hart (1996) found that girls were more likely to tell stories that stressed their own safety consciousness, and their
acceptance of responsibility for the safety of others, whereas boys were more likely to tell stories about risks that were deliberately courted. Girls as young as seven years of age (the youngest interviewed) were much more likely than boys to express feelings of responsibility for the safety of younger children. Girls were also more likely to say that they would not repeat the particular adventure, that they would learn from experience. Peers who took careless risks were not supported, but conversely, were often the subject of contempt. The authors concluded that girls were more likely to present both themselves and other girls as responsible risk managers, and to create gender appropriate identities and gendered notions of responsibility in their talk about risk taking. Thus, girls may be responding to stereotypical expectations of femininities as being self-sacrificing, docile and virtuous (Coppock et al. 1995).

James (1993) found gendered ideas about responsibility in the school setting when she examined the power relations structuring the performance of the dyadic relationships of six year old girls, noting:

These are the keys to understanding the experiential aspect of girls' friendships which are both structured by, and provide the contexts for, the caring-control which, in their future role as adult women caring for dependent others, they are being elsewhere socialised to adopt. That is to say, the power to care for others can, at the same time, be construed as a form of control and it is through their dyadic friendships that the double-edged quality of care is both experienced and made manifest to girls (1993: 228).

She illustrates this idea by discussing the friendships with younger children that many of the six year old girls had, stating: 'these little(er) children can be cared for and mothered in the same moment as a girl's 'bigness' is made public' (1993: 228). In contrast, the boys' friendships were less exclusive, making it easier for boys to drift from group to group, and boys caring for younger boys was rarely seen.

In terms of young people, the fact that responsibility for care appears to be gendered may impact on the different ways in which teenage girls and boys manage chronic illness, particularly illnesses where a high degree of self-management is involved. As Oakley states:

There is nothing biologically inevitable about the gender differences....all the evidence is that these result from an unequal pattern of socialisation in which girls are sensitised to the need to care for others and boys are given the message that real men don't care (1994: 433).
2.2.2 Gendered Dependency

When discussing how various forms of dependency are gendered and differentially evaluated by society, Arber and Ginn observe that:

...the dependence of men on women for domestic/caring services...are rarely acknowledged as dependency and entail little if any loss of autonomy, status or power. If all people are dependent, some are more so than others, in terms of the subordinate status they acquire as a result of their dependency (1991: 67).

Dependence can be seen to have gendered meanings, and in terms of boys and men, Lees states: 'Masculine identity is constituted in opposition to everything feminine. It involves denial of dependence' (1993: 306). In examining how young men acquire masculine sexuality, Holland et al. also found that in order to achieve 'successful masculinity' men were placed under pressure to: 'conceal the extent of their vulnerability through caring, dependency, loving and any other characteristic of nurturing or effeminacy' (1993: 2).

However, this denial of dependence can impact on the partners of men, and when exploring how men adapted to chronic illness, Charmaz found:

...partners often find themselves in an elaborate dance around dependency.... these women provide identity supports for their partners that mute the identifying effects of dependency and loss (1995: 282).

In his research on men with testicular cancer, Gordon (1995) also found that in most cases he was the first person with whom the men had discussed their experiences. In general, he found that the men handled their feelings associated with having cancer by attempting to deny or hide them. As a consequence, Gordon found that in many cases the men's wives were left doing the emotional work for them, thus being cast in the expressive role of providing emotional support for their husbands, which in turn led to them becoming 'emotionally agitated' themselves. Similarly, in their study of 300 patients with cancer, Fife et al. (1994) found that the men used a more task-oriented approach, whilst the women focused on altering their emotions and mobilising family support. The authors argue that the men made a less positive psychosocial adjustment than the women did, and that this could also result in the partners of men doing emotional work for them.

This gendered notion of dependency is a key one in terms of the proposed research. It relates to the gendered ways in which mothers may care for their children, and it may affect
how young people take responsibility for self-management. The concepts of dependence and independence are closely linked to the concept of autonomy, which will now be discussed.

2.2.3 Gendered Autonomy

Autonomy is a concept which has proved difficult to define, and this has led to it sometimes being confused with the concept of independence. In relation to disability, Williams and Wood clearly highlight the differences between these terms, stating:

The notion of independence fails to convey the continuing self-determination manifest even when disability is so severe as to compel greater dependence on others. What actually happens is a shift in the balance of customary interdependence, so that the changes are only relative rather than absolute.....The two concepts are certainly connected logically, but autonomy preserves greater awareness of possibilities for power and action (1988: 131).

Williams and Wood see autonomy as a social process rather than merely an individual attribute, and they claim that the key hindrances to autonomy are arbitrary power, ill-health and ignorance, stating:

Autonomy emerges from relations of power between people in specific settings, and chronic illness creates various points at which the person can experience loss of power in relation to activities and relationships (1988: 132).

Their work highlights some key issues relating to independence, autonomy, and the importance of power relations. The research proposed will examine these issues in relation to young people, who may also be in a less powerful position because of their age.

Alderson and Montgomery state that autonomy is a concept related to social age, and they define it in two main ways:

First, as qualities within the individual, autonomy involves the conscious sense of self and of physical and mental integrity and the capacity to make informed and wise decisions....Secondly, autonomy is the activity of self-determination, of actually making informed choices and having control over one's own life. The second meaning is often confused with the first: when children do not have opportunities or permission to demonstrate their autonomy, it is often mistakenly assumed that they do not have the personal qualities or the capacity for autonomy (1996: 18).
This definition is a useful one in that it separates the conscious sense of self from the activity of self-determination, thus allowing a sensitive exploration of any differences which might be found amongst young people. French's (1993) work on disability illustrates the activity of self-determination from a different perspective. She draws on the work of Shearer (1981), who believes that to insist on independence is a form of oppression which removes control from the individual. Although health professionals and parents do not usually insist on independence in relation to self-management, they may exert subtle pressure on young people with similar consequences. In this way, young people may also be denied self-determination.

The proposed research will explore the extent to which concepts of dependence, independence, and autonomy are gendered, and the ways in which this impacts on young people with a chronic illness. The research also aims to develop the work of Silverman (1987c), who observed outpatient consultations between doctors and adolescents with diabetes. Silverman states that autonomy presupposes independence and responsibility, and he describes how, once the patient has been defined as an active decision-maker, she or he gains autonomy at the expense of being held morally responsible for her or his actions, stating:

If rewards and sanctions are the means of maintaining discipline with children, then the production of feelings of guilt is a subtle means of control when they are granted autonomy (1987c: 213).

However, Silverman's work did not analyse gender differences in relation to gaining autonomy, or in the use of guilt as a means of control. This research will explore the impact of gender on gaining autonomy, and the consequences that this can have for young people when managing a chronic illness.

2.3 Gendered Embodiments and Power Relations

The development of gendered identities incorporates the development of gendered embodiments and embodied power relations. Firstly, this section will discuss ways in which gendered embodiments may develop, and how these embodiments relate to meanings of health. It will then discuss the differential impact of embodied power relations.

2.3.1 The Development of Gendered Embodiments

The development of gendered embodiments is important to the proposed research because the body can be seen as: 'a site where sickness and health are played out' (Morgan and Scott
1993: 7). In addition, Morgan and Scott argue: 'It is clear that bodies receive, rather than simply confer, gender' (1993: 9). In relation to the sociology of the body, many of the studies deal with women and the female body, and Morgan (1993) highlights this tendency to see women as somehow more embodied than men. The proposed research aims to explore the ways in which gendered embodiments affect the management of chronic illness in both young women and young men.

Morgan (1993) also argues for a plurality of masculinities, and in this study the terms masculinities and femininities will be used to denote this. When assessing current ideas in relation to masculinities, Weeks (1996) draws on the work of Connell (1995) when he states that human practice is 'onto-formative', thereby constructing the reality in which we live. He argues that masculinities are constructed through 'body reflexive practices' which make up a world that is not bodily determined, despite having a bodily dimension. However, Weeks (1996) points out that embodiment is not just about the physical processes through which the social is embodied, but that it is also about feelings and emotions, and this view of embodiment can apply equally to the ways in which femininities are constructed.

Children and young people spend a large part of their lives in school, so the school environment is important when considering socialising influences on the development of gendered embodiments. Through her research on girls aged 13 to 16 years, and the ways in which school influenced their experiences of menstruation, Prendergast (1995) examined the development of gendered embodiments. She found girls operated constant surveillance in many areas in order to: 'manage menstruation with proper discreetness - in essence total invisibility - in school, and girls blamed themselves if they failed' (1995: 354). In seeking to understand why girls acted in this way, she explores some dominant themes.

Firstly, Prendergast (1995) states that the adolescent body is responding to the scrutiny of the predominately male gaze, and she believes that at no time are heterosexual values more powerfully pursued and enforced than during adolescence. In contrast to the ways in which girls and women must usually produce their bodies for the judgement of men, Prendergast feels that the girls' accounts serve to illustrate the ways in which the body: 'must be repressed, guarded and contained so that its secrets could not be known' (1995: 357). Prendergast (1995) states that this embodied knowledge is built up through the life-course, drawing on the work of Young, who believes that:

..the young woman learns to constantly live her body as an object, as other, as the intention of another subject, rather than as a living manifestation of action and intention of her own (1989: 155).
This theme is also echoed in research looking at the ways in which women manage the menopause (Darke 1996). Darke found women operated a practice of 'just getting on with it', concluding:

..women silently get on with menopausal problems, particularly in relation to work...this expectation may be more about maintaining gendered social hierarchies than an aesthetic practice of the self (1996: 152).

Another dominant theme described by Prendergast is that of menstruation as loss of control, and consequently, as an attack on self:

Clearly defensive body postures, watchfulness, secrecy, anxiety, stress, all the things that girls describe in school, are not natural correlates of menstrual experience, but might come to shape, quite literally our sense of self (1995: 359).

Prendergast (1995) proposes that early menstrual experiences rehearse adult roles, drawing an analogy with the work that makes up the 'proper' role of women in managing the bodies of babies, children, the elderly, the sick, and husbands, as carers both at home and at work:

Again, as in the presentation of her own body as object of the gaze, it gives women the task of both producing the social and collective body.... and repressing it... while these tasks must be done, it is essential that they are done discretely, invisibly, must not intrude (1995: 360).

With reference to her research with Forrest (Prendergast and Forrest 1997) on the effects of school on gender and embodiment, Prendergast (1996) has highlighted various ways in which the formal and informal aspects of school affect young people. Prendergast (1996) found that gendered embodiment was being both shaped by, and shaping, the use of both formal and informal spaces in the school, as boys established or increased their control over public space. This was related to the fact that boys were using their bodies much more actively than girls, who as Prendergast notes, often give up or decrease the amount of sport played during adolescence. Prendergast also found a very close interlinking of masculine embodiment and the emotions, stating:

..boys give priority to embodiments that are impervious, hard. They learn physical ways of coping with emotions: boys literally pass emotions on. get rid of them. Boys shove and fight. In contrast, girls talk (1996: 12).

Prendergast draws on the work of Connell (1987) when she states that gender is not static, but is constantly being remade and reaffirmed. In this way, she suggests: 'we not only
gender/embody ourselves, but that we all of us make gender/embodiment more widely, for each other' (1996: 13). Prendergast's work is important to the proposed research which will explore the differential meanings that asthma and diabetes may have in terms of gendered embodiments.

White et al. (1995) highlight the particular importance of risky sport and injury experiences for adolescent boys in terms of their transition to adult masculinities, and the importance of the institution of sport which serves to construct and reconstruct masculinities. They draw on the work of Connell who states:

Sport is, all considered, astonishingly important. It is the central experience of the school years for many boys, and something even the most determined swots have to work out their attitude to (1983: 18).

In addition, the importance of sport might relate to the meanings that preventive health and medication have in relation to masculinities, as highlighted by White et al., who state:

Learning to use the sporting body for boys and men implies also learning to detach oneself from it. As a result, sensitization to bodily well-being and matters of preventive health in general become viewed as the jurisdiction of women and "ambiguous" men (1995: 180).

The importance of sport and physical action both in relation to masculine embodiment and as a way of handling emotions is again highlighted in relation to boys, as opposed to girls of this age, and the proposed research will explore whether these gendered meanings impact on disease management.

To understand what chronic illness might mean to a young person, it is helpful to look at the gendered meanings of health, and the ways in which health is embodied. When researching the meanings of health to adults, Saltonstall found gendered differences:

Men frequently referred to healthiness as 'keeping' or 'being in control' and 'minding' one's body. Men seemed to imagine themselves as having 'power over' relationships to their bodies....Men spoke about their bodies as though they 'belonged' to them (in the same way that an object belongs to one). Women, on the other hand, generally did not use the language of ownership when talking about their bodies, but rather referred to their bodies as though their bodies had a momentum or subjectiveness of their own (1993: 9).
The significance men appear to place on 'being in control' may be important in terms of the management of chronic illnesses, many of which have some degree of unpredictability. Saltonstall (1993) noted further differences in respect of body maintenance. He found men to be far more concerned than women with the body as a medium of action, with the function and capacity of the body seen as crucial. This supports earlier research such as that by Blaxter (1985), who found that men had a functional health belief where good health was seen as being able to do things such as playing sport and going to work, and poor health was seen as the opposite. Although women were also concerned about these issues, particularly in relation to 'doing for others', they were just as concerned with the outward appearance of their bodies.

Saltonstall (1993) states that the concept of body maintenance reflects a conceptualisation of the body as having an 'inner' and 'outer' aspect. He draws on the work of Young (1989), who states that body identities have been dichotomised into women-body-as-passive/man-body-as-active, following on from Cartesian dualism. It appears that women and men have different ideas about what bodies should look like and how they should function, which relate to social norms about gender and the body. In relation to being healthy the actions taken were heavily influenced by ideas about what constitutes appropriate masculine and feminine behaviour. Saltonstall concludes:

"..the doing of health is a form of doing gender. This is not because there is an essential difference between male and female body healthiness, but because of social and cultural interpretations of masculine and feminine selves - selves which are attached to biological male and female bodies. Health activities can be seen as a form of practice which constructs the subject (the 'person') in the same way that other social and cultural activities do (1993: 12)."

2.3.2 Embodied Power Relations

The notion of embodied power relations relates to the ways in which certain femininities and masculinities are seen as more dominant within particular societies, and the proposed research will explore the gendered ways in which chronic illness impacts on embodied power relations. In her research on young people, Prendergast (1996) found evidence of embodied power relations such as oppressive behaviours from boys to girls, and from boys to other boys. She found the latter very much depended on what she called 'unfair' characteristics such as body size, over which boys had little control. Body size, particularly height, can be affected by both asthma and diabetes, and blunting of the pubertal growth spurt has been consistently observed (Salardi et al. 1987). Prendergast (1996) draws on the work of Simmons and Blythe (1988) when she comments that for boys, size, and
particularly height, serves to categorise them not just in terms of age, but also in terms of maturity. She states:

Small boys are not just physically immature but judged as immature in all other ways too. They must accept their lower place in the order of things (1996: 10).

This relates back to the ways in which age is socially constructed and means, according to Prendergast (1996), that power is seen not only to derive from relatively 'acceptable' characteristics such as age, but also from characteristics which are 'unfair and arbitrary', such as height. Prendergast found these patterns of power to operate in circular and self-perpetuating ways, within a closed system, stating: 'this off-loading of violence acts like a web which catches even those who wish to have no part in it' (1996: 10). This draws on the work of Connell (1987), who suggested that certain masculinities are seen as more dominant than others within particular societies. However, Morgan (1993) argues that although the idea of a hierarchy is more useful than a simple plurality of masculinities, the relationships between hegemony, embodiment and gender are not straightforward, as there are many ways and sites where gender and bodily power can interact.

In terms of disability, Morris (1993) states that because dependence is a key part of both the social construction of gender for women, and the social construction of disability, women's powerlessness is confirmed by disability. She contrasts this with the experience of men who are disabled, whom she feels may experience a conflict between their 'masculine' and 'disabled' roles, using masculinity as a way of resisting the disabled role. However, Morris highlights the ways in which men's experience of disability can be dominated by the social construction of masculinities, when drawing on the situation of one man who became tetraplegic following a motor-bike accident:

Both work and leisure activities.....were linked with physical ability, and both these areas of his life were characterised by the social meanings of masculinity. Once his physical ability to do these 'male' activities was removed, he was status-less, role-less, and this was articulated by his wish to die.....It is outrageous that these structures of oppressions caused a young man to think that if he couldn't play football then life wasn't worth living (1993: 90).

Although chronic conditions such as asthma and diabetes may not be comparable with tetraplegia, they could for many reasons be seen to contain unwanted elements by which boys could be pushed into a lower place in male hierarchies, perhaps more so than the effects on girls within female hierarchies. The proposed research will explore the differential
gendered meanings that chronic illnesses may have, focusing specifically on asthma and diabetes.

The gendered meanings of chronic illness will be the theme of the next chapter, but the personal narrative of a young Finnish writer (Tiihonen 1994) will be discussed here, as it illustrates the ways in which disease can affect gendered embodiments. Tiihonen discusses how the 'construction' of his body was affected by asthma, highlighting the importance of the: 'healthy, sporting, and disciplined body inscribed in hegemonic masculinity' (1994: 51). In relation to sports training he states:

..my skills, power, speed and even endurance improved. And yet, I felt that the limits of my capability were continuously on trial, on the threshold of pain (1994: 53).

He describes how he learnt that masculinity was defined through denial, through what a man should not be:

By rules, hidden fears and the insolent language of the gang....we became men....dispassionate masculinity, which is experienced negatively, had to stand unaffected by all the attacks directed at it (1994: 55).

This narrative highlights some of the difficulties which may be experienced by young men with a chronic illness when attempting to conform to the socially acceptable 'face' of masculinity. The importance of sport to the construction of masculinities is again highlighted, as are the ways in which chronic illness can impact on this.

2.4 Conclusions

This chapter has focused on those aspects of gendered identities which may impact on ways of living with and managing chronic illness during adolescence. Firstly, the chapter explored the ways in which the concepts of adolescence and transition have been socially constructed, and how this has impacted on research relating to young people. The proposed research will attempt to incorporate these ideas into a theoretical framework using a life-course approach, thus enabling young people with a chronic illness to be placed within the family, yet taking account of the wider social, structural and historical processes impacting on them. The research will promote the view of young people as key actors, and will look critically at the effects that the concepts of transition and adolescence may have on their lives, particularly in relation to the negotiation of independence. A key focus of the proposed research will be to explore how gender interacts with the social constructions of
adolescence and transition, and the ways in which this interaction affects the ability of young people to make transitions.

The chapter then focused on specific aspects of gendered identities which may impact on disease management during adolescence. Three areas relating to the gendered meanings of responsibility and dependence were explored. Firstly, the gendered ways in which young people learn to care were examined and linked to gendered notions of responsibility. Gendered dependencies and notions of autonomy were also explored, and Silverman's (1987c) work on young people and autonomy was noted. The proposed study will explore both gender differences in relation to gaining autonomy, and the differential gendered effects of using guilt as a means of control.

Lastly, this chapter explored some of the ways in which gendered embodiments and embodied power relations might impact on living with and managing chronic illness. The gendered meanings of health were related to embodiment, and the notion of gendered hierarchies was discussed in relation to the ways in which asthma and diabetes might impact on femininities and masculinities.
Chapter Three

SELF - MANAGEMENT OF CHRONIC ILLNESS

This chapter will focus on key aspects of managing chronic illness which may be important to young people. The term self-management appears in much of the medical literature in relation to asthma and diabetes, and the treatment of both conditions is seen by health professionals to involve a large element of self-management. However, the term itself is not a neutral one, and the meanings and implications of this will be discussed. The key concepts of self-help and self-care are relevant, and these will also be discussed and clarified, as there is a tendency for all three concepts to be used interchangeably. A historical overview of the emergence of self-help and self-care will be taken, as this helps explain current attitudes and meanings in relation to self-management. This chapter will then explore the meanings of compliance, particularly in relation to asthma, diabetes, and young people. Finally, literature relating to the gendered management and meanings of chronic illness, including stigma, will be discussed.

3.1 Self-Management of Chronic Illness

This section will explore the concept of self-management in relation to chronic illness. Firstly, the linked concepts of self-help and self-care will be examined, as these both influence current understandings of the term self-management. These three terms are often used interchangeably, and this section will serve to clarify the meanings of each.

3.1.1 The Emergence of Self-Help

There are two opposing views of self-help which Wood and Williams (1988) believe may lead to tensions in the notion of self-help, and may also contribute to difficulties in achieving apparent aims. The first view stems from the individualistic tradition which emerged through the social transformations of the Reformation, the Renaissance and the Enlightenment, in opposition to medieval corporatism (Williams 1989). In relation to the passing of Poor Law legislation in England early in the 17th century, Chrichton states that this:

...established a set of principles that guided social welfare provision in Britain and its colonies for the next three centuries....individuals were expected to help themselves to survive in bad times as well as good by provident,
foresighted behaviour. If self-help failed, then it was their extended families' responsibility to assist (1981: 160).

This ideology was personified by Samuel Smiles in his book, 'Self-Help, with Illustrations of Character, Conduct and Perseverance', published in 1859, which was the apotheosis of middle-class Victorian values. Smiles believed that outside help was: 'often enfeebling in its effects', and that the best institutions: 'leave man free to develop himself and improve his individual condition' (1859: 22). He thus linked self-help with both moral and economic self-sufficiency, an attitude which affects present day perceptions of health and illness. The second view of self-help in the collectivist tradition emerged from the medieval guilds and, more recently, from the trade unions and friendly societies. Wood and Williams (1988) believe that a knowledge of these opposing views facilitates an understanding of the sometimes contradictory elements of self-help initiatives related to health, concluding that:

Superficially, it might seem that such groups simultaneously reconcile independence, equated with self-reliance, and a desire for mutuality or reciprocity. But self-help, like Janus, has two faces; in one guise it celebrates individual freedom against a corporatist state, however illusory or limited this freedom is in practice, and in another it articulates communal defence of the entitlement to public resources, however paltry and dehumanizing these may be in reality (1988: 136).

Various reasons for the recent renewed interest in self-help have been suggested. Levin et al. (1976) link it to the general spirit that emerged during the 1960s, particularly trends such as the civil rights movement and the feminist movement. These movements emphasised the questioning of both the authority of established institutions, and the correctness of their points of view (Kronenfield 1979). Following on from this, Perlman (1976) characterises the movements of the 1970s as grassroots associations which emerged from the disillusionment of ordinary people with governments, leading them to feel the need to act for themselves.

When researching the role of self-help groups in chronic illness, Williams (1989) found an uneasy partnership between individualism and collectivism. Using the National Ankylosing Spondylitis Society (NASS) as a case study, he states that at a national level:

NASS is imbued with an individualistic notion of self-help which seems to have been sustained by the dominance of middle-class professional values and interests (1989: 152).

Williams (1989) felt that the tensions he noted in NASS related particularly to condition-specific groups, and were reinforced by three factors. Firstly, he states that there is more
likelihood of help being sought from doctors, making the group more vulnerable to medical
dominance, with a consequent emphasis on the importance of the physical problem.
Secondly, Williams (1989) noted a focus on stigma, adaptation and coping as psychological
problems, with an emphasis on personal as opposed to social change. Thirdly, he felt that
by focusing on a specific condition as opposed to a variety of conditions with similar social
consequences, the actual process of self-help could emphasise individual responsibility, thus
reinforcing inequalities in the provision of health services. It will be seen that all three of
these factors are embedded in the concept of self-management.

Many self-help groups promote the idea of self-care in relation to chronic illness, and this
concept will now be discussed.

3.1.2 Self-Care

There are many definitions of self-care. Wood and Williams (1988) use that of Kickbush
and Hatch, who define self-care as:

..unorganized health activities and health-related decision-making by
individuals, families, neighbours, friends, colleagues at work, etc; it
encompasses self-medication, self-treatment, social support in illness, [and]
first aid in a "natural" setting i.e. the normal social context of people's
everyday lives (1983: 4)

Maclean uses a broader definition of self-care, defining it as representing: 'the range of
behaviour undertaken by individuals to promote or restore their health' (1991: 689). The
advantage of this definition is that it includes self-care actions in either the presence or the
absence of medical supervision, and it is therefore useful in relation to chronic illnesses such
as asthma and diabetes where some degree of medical supervision is usually present.
However, others argue that self-care is not necessarily an individual undertaking. Barrett
and McIntosh state that although the ideology of individualism appears to reject dependency
on other people and social groups, it is often the case that: 'in practice, the unit of self­
support is not the individual but the family' (1984: 45).

The reasons for the renewed interest in self-care are similar to those identified in relation
to self-help. Crawford (1980) believes that during the 1970s the middle-class population
was forced to adjust to a world of increasing insecurity and uncertainty in relation to health,
economic life, and personal relationships, stating that: 'when life is experienced as eluding
control...the need for personal control is intensified' (1980: 382). He views the growth of
self-care to be one manifestation of this desire to reduce the reliance of individuals on
medical practitioners. The failure of health professionals to meet the needs of those with chronic illnesses has been noted by many researchers (Vincent 1992), and this is related to the realisation of the limits of modern medicine.

An earlier critique of medical practice which supported the growing interest in a reappraisal of priorities was that by Illich (1975), who expressed doubts about the value of expanding the role of medicine. He regarded the harmful effects of medicine as being not only of a clinical nature, but extending into the social sphere, through reducing people's autonomy and increasing their dependence on medical care. McEwan et al. (1983) believe this view to be part of a wider issue which they call 'the crisis of contemporary professionalism', characterised by the inflexibility and impersonal nature of the health service, criticisms of the bureaucracy involved, and an awareness of the limitations of modern medicine. Robinson and Henry (1977) support this view, believing the increasing importance of self-care to be due to a growing interest in holistic care, together with a growing hostility towards any professional health care system that undermines the power of the individual in shaping their own environment.

Criticisms have been directed towards aspects of the ideology of self-care. Williams (1983) questions the extent to which organisations such as the Independent Living Movement, who have agitated for increased self-care, are representative of 'the disabled', stating that: 'the core consistency of the Independent Living Movement is young, male and 'fit' as opposed to 'frail' ' (1983: 1005). Anderson (1990) believes that caution should be exercised by health professionals, who tend to assume that the policies promoted by these organisations are in everyone's best interests, failing to recognise the complex factors that influence people's day to day management of chronic illness.

Macintyre (1986) also highlights the potential that the self-care movement has for 'victim blaming', by which people can be accused of causing their ill-health. Macintyre (1986) identified a major shift away from viewing the processes which intervene between social position and health outcomes as being outside individual control, to them being viewed as largely within individual control. This approach was encouraged by government reports which emphasised so-called 'voluntary behaviours' at the expense of structural solutions (Ashton and Seymour 1988). As Blaxter (1990) states, the idea that health has a moral connotation is not new, and contemporary health policy which equates health with virtue merely reinforces a deep-seated concept. In her research she found that: 'the apologetic air with which those who were not healthy spoke about their health was a pervasive impression, even in this largely structured survey' (1990: 243).
This shift in emphasis may particularly disadvantage those with chronic illnesses because of changing attitudes towards them, and the fact that their symptoms may limit the adoption of 'healthy lifestyles' (Bury 1991). As Williams (1989) remarks, moral self-sufficiency and consumer sovereignty serve to conceptualise the individual as self-defining, whereas in reality an individual is only relatively autonomous within a network of social forces. With the increasing emphasis on self-care, he argues that there needs to be an equal recognition of the structural, social and economic factors which mediate both the experience and the management of chronic illness. He also believes that health policy decisions are needed which recognise the difficulties that self-care can bring, with the allocation of adequate resources. However, one of the major problems in many countries is the escalating cost of health care, combined with the need to deliver effective care to consumers. Cost effective methods of health care delivery are a high priority, leading Anderson to predict that:

"...one trend in health care delivery that one suspects will gain even greater momentum in the future is the move toward self-care and home care management for people with a chronic illness (1990: 71)."

In addition, Anderson (1990) remarks that although the self-care movement could be seen optimistically as the beginning of a more humanistic perspective on the part of health professionals, economic policies have also had a major part to play in the rise of these new directions in health care delivery. In relation to her research on families looking after a child with a chronic illness, Anderson (1990) found that the lack of adequate resources available to help individuals and families take on responsibility for care was one of the major barriers to successful home care and self-care.

3.1.3 Self-Management

The terms self-management, or 'guided' self-management, are frequently used in biomedical literature in relation to people with chronic illnesses such as diabetes and asthma, but they are rarely defined or explained. In one of the few definitions found, Goodall and Halford state:

"A preferable term is self-management, which suggests a set of skilled behaviors engaged in to manage one's own illness....It also circumvents the authoritarian tone implied by a term such as compliance (1991: 1)."

However, this definition appears to accept the term unproblematically, and in relation to the self-management of diabetes and asthma the term (non) compliance is frequently applied. Self-management differs from most definitions of self-care in that it usually refers to a
flexible regime pre-determined by the health professional, which the 'patient' then follows at home. Bytheway and Furth comment that: 'a particularly high level of responsibility for asthma treatment is carried by lay people', and note that: 'diabetes mellitus is one of the few other potentially life-threatening conditions with a similar level of personal responsibility for 'juggling' treatment' (1996: 106). To illustrate the level of responsibility in relation to asthma, they state:

Asthmatic symptoms fluctuate in response to environmental triggers, which are themselves highly variable. Thus, the patient or parent has to judge whether to use a reliever or a preventer drug sporadically or routinely, how much medication to give and how soon, whether to increase the dose in anticipation of a certain trigger, what significance to place on self-administered peak-flow measurements, and finally when to seek medical help and with what degree of urgency (1996: 106).

However, in this 'guided' self-management health professionals maintain power and control through surveillance, dictating the actions of people with regard to self-management. Health professionals define the limits, and 'patients' have regular checks to see whether or not they are keeping within the guidelines. This differs from most definitions of self-care where individuals have the power and control to decide on their own actions, and as a consequence, the notion of compliance is not an issue. With self-management, control, non-compliance and blame are key issues which emerge as a consequence of health professionals having power and control. This situation may be even more accentuated in relation to people with asthma and diabetes, both of which carry very high levels of personal responsibility in terms of management. As Posner states:

Independence of judgement by the patient about his or her condition may be praised where it results in action of which the doctor approves, but not where it clashes with the doctor's judgement about what is best for the patient (1988: 125).

This is one of the contradictions of 'guided' self-management, in that people are encouraged to be aware of their bodies, but when it comes to trusting this knowledge they are told that it may be unreliable, and that they should rely instead on mechanical devices such as peak flow meters and blood glucose meters. This can lead to an individual's own experience and knowledge of her/his body being devalued in comparison to the information gained from mechanical devices, and the emphasis that doctors place on the latter. Wood and Williams (1988) note the importance of knowledge in asserting power and autonomy at an individual level, and it seems that in self-management the status of the individual's knowledge makes the exercising of power and autonomy more difficult. 'Guided' self-management may therefore be disempowering, as the power to grant approval or disapproval lies very much in
the hands of the medical profession. This is similar to Oakley's (1980) findings in relation to pregnancy, where women's experiential knowledge of their bodies was devalued against the doctor's 'expertise'.

'Non-compliance' and blame can also result in the use of perjorative terms by health professionals such as 'cheating', which was discussed earlier in relation to brittle diabetes. Maclean and Oram (1988) found that some of the people they interviewed used the term 'cheating' to describe the actions they were taking to 'stretch the limits' of self-management in terms of diabetes. As the authors state, cheating has a negative connotation because it implies breaking the rules which are set down by health professionals. However, viewed more positively, cheating can be seen as a way of learning through experimentation, a way of taking responsibility in order to find a balance that suits the individual.

In relation to self-management there may be a gendered impact, in that girls may be expected - and may expect themselves - to act more responsibly than boys (Green 1997). However, the meaning of responsibility in this situation may be problematic as it implies taking responsibility for oneself, and acting in a responsible way, but in terms of self-management, responsibility means following pre-determined, authoritative guidelines. The medical discourse around self-management is that 'patients' have control, but the reality may be very different. Taking a Foucauldian approach, Silverman (1987a) highlights the problems he sees as inherent in the emerging 'whole person medicine'. He states that whilst 'social' made medicine is less authoritarian than its preceding biological model, it may ultimately be more intrusive. He comments that:

..on the one hand, the theoretical subject is free to respond and to choose. On the other, she is forced to respond and choose and is held to account for those responses and choices. So the greater involvement of the patient in the consultation is both emancipating and constraining (1987a: 225).

In other words, surveillance - and blame - exist just as much, if not more, when patients are treated as 'free subjects', as when professionals treat patients as objects of the clinical gaze. In relation to both diabetes and asthma, great emphasis is placed on the fact that most individuals (children and adults) can gain good control if self-management is carried out 'correctly'. The resulting problems are well illustrated by a letter from A. Hayward, published in Asthma News:

I feel there is a danger that asthma could be seen as self-inflicted if the message of self-management is misunderstood by the public. I have recently been off work with a bad spell. I was determined to go to the supermarket
I had comments about being pathetic for my age and that people grow out of asthma; I was accused of having asthma by heavy smoking: worse still, I was told to calm down. It made me wonder if all this positive publicity about asthma being 'controllable with the right management' had gone too far (1994: 13).

This section has explored the meanings of self-help, self care and self-management, three concepts which are often used interchangeably. The relatively new concept of self-management has been placed in a historical context. The contradictions of this specific kind of 'guided' self-management have been discussed, particularly in relation to power and control. The possible consequences of 'guided' self-management were highlighted, particularly those of non-compliance and blame of the individual. It was suggested that these consequences may be gendered, as girls are often expected - and expect themselves - to act more responsibly than boys. Compliance is an important focus of the proposed research, and the following section will explore this concept, particularly in relation to young people with asthma or diabetes.

3.2 The Meanings of 'Compliance'

When chronic illness involves a medical regime, self-management relies to a great extent on individual adherence to treatment. Adherence and chronic disease management are complex issues, affected by many factors. In his classic study, Stimson (1974) argued that the notion of the doctor as expert and the patient as passive was taken for granted, which led to the patient being blamed for any 'non-compliance'. The term compliance has been criticised for being a value-laden term, closely linked to medical dominance (Donovan and Blake 1992). However, Thorne (1990) suggests that changing terms, such as calling 'non-compliance' 'non-adherence', does little to redress the power imbalances that surround the area of compliance.

Much of the professional literature is based on the ideology that non-compliance is deviant behaviour, leading to the blaming of patients (Donovan and Blake 1992). Whilst there is more emphasis now on the subjective meanings of non-compliance, Thorne (1990) states that most of these studies investigate health beliefs with the intention of predicting and preventing non-compliance, rather than understanding it. Consequently much of the literature recommends various ways of treating non-compliance, such as providing more information and education, behavioural therapies, or improved socialisation into the patient role (Boehnert 1986). In the case of children with a chronic illness, families, particularly mothers, can be blamed for poor compliance (Askilden et al. 1993). From the medical perspective compliance is seen as an integral and essential part of self-management. However, Lowenberg (1989) comments that after trying to motivate patients, doctors no
longer feel that non-compliance is their responsibility, and he states: 'Practitioners have never defined 'non-compliance' as their failure within the traditional medical model' (1989: 177).

Sociological research has focused on the meaning of medication in people's everyday lives. With regard to epilepsy, Conrad argues that from a patient's perspective the issue is more one of active self-regulation than compliance:

...regulating medication represents an attempt to assert some degree of control over a condition that appears to be completely beyond control...framing the problem as self-regulation rather than compliance allows us to see modifying medication practice as a vehicle for asserting some control over epilepsy (1985: 36).

Conrad (1985) found various meanings of self-regulation which included 'testing', to evaluate how epilepsy was progressing by reducing or stopping medication; 'controlling dependence', by changing a prescribed medication; 'practical practice', where people changed their medication practice to suit their everyday lives; and 'destigmatisation', where people developed skills to minimise the potential stigmatisation which might result from taking pills in public. Conrad's respondents found it more difficult to hide the meaning of the medications from themselves, and he found that for some people: 'it is as if the medication itself represents the stigma of epilepsy' (1985: 35). However, Conrad did not explore the impact that gender might have on the meanings of self-regulation.

When investigating the concept of compliance in people with rheumatoid arthritis, Donovan and Blake (1992) found it to be largely irrelevant, as respondents carried out a 'cost-benefit' analysis of each treatment, weighing up both the costs and the risks of each treatment against the benefits as they saw them. The authors conclude that the solution to non-compliance will not be found by attempting to increase patient compliance, but in the development of more co-operative doctor - patient relationships. However, Thorne (1990) believes that in general, health care professionals have very little to offer people with a chronic illness until they re-examine their claim to expertise and 'moral authority' in the area. She states that for those with a chronic illness, the main emphasis is on how to live well from day to day, and she believes that non-compliance should be seen as: 'a rational form of social responsibility, consistent with the type of independent health care maintenance advocated for the non-chronically ill population' (1990: 67). She also criticises the health care partnership so often advocated by health care workers as arrogant, believing that workers should instead aim for credibility in their relationship with chronically ill experts.
3.2.1 Compliance and Young People

In relation to both diabetes and asthma, health professionals encourage young people to take responsibility for self-management, often encouraging them to attend clinics on their own. However, the idea of young people being treated as experts or even as equals in their relationship with health care professionals may be problematic. Szasz and Hollender (1956) identified three types of doctor-patient relationship in a typology which has been very influential, although it was based on the context of a shared belief in the biomedical model. 'Mutual participation' was the relationship seen as most suitable for those with a chronic illness, but Lowenberg (1989) questions whether this is as seen from a middle-class perspective. It is even more difficult to see how young people with a chronic illness would fit into this model of 'mutual participation', because of both their perceived dependency which relates to their age, and issues of power and control in relation to consultations.

Hingson et al. (1981) suggest that there is little consistent relationship between non-compliance and factors such as age and sex. However, other studies indicate that compliance is a particular problem for adolescents in relation to a wide variety of conditions (Lilleyman and Lennard 1996). In relation to both diabetes and asthma, there are many studies showing that young people appear to have the poorest adherence and disease control compared with other age groups (Birkhead et al. 1989; Bobrow et al. 1985). Similar findings are reported for a wide variety of conditions, including the compliance of paediatric and adolescent patients with cancer (Cameron et al. 1986). Miller et al. (1993) state that for many young people in the process of establishing an independent adult identity, peer group approval is important, and may take priority over maintaining medical regimes even when the adverse consequences of non-compliance for health are understood.

Gender is often a 'hidden' factor in biomedical research because it is assumed that the cause of poor control is physiological, not social. In addition, gender issues are often present in research on compliance, but may be ignored. For example, in relation to follow-up treatment for childhood leukaemia (Davies et al. 1993), six out of 22 children showed wide fluctuations in the concentrations of a particular drug's metabolites. This is important because the dose may be escalated for these patients, which could be dangerous if the problem is non-compliance. Gender is not commented on, despite the fact that the authors found: 'Two children admitted failing to take their tablets. Both were adolescent girls in charge of their own treatment' (1993: 1240). As was the case in relation to brittle diabetes and asthma, little attempt was made to understand why non-compliance occurred, and Davies et al. conclude: 'Serial assay of metabolites can be used to monitor suspected offenders, but continual vigilance and education in the clinic are also needed' (1993: 1240).
In one of the few studies to explore in any depth the issues of gender and compliance in young people, Miller et al. (1993) found gender affected important areas of cystic fibrosis management. Their research findings will be discussed in detail as they are important in terms of the proposed research. They found striking differences between teenage girls and boys in relation to compliance, in the three key aspects of treatment which were examined; exercise, nutrition and physiotherapy. In relation to exercise, young women were found to be much less physically active, although they all knew that exercise would be good for their health. The authors argue that the social construction of femininity for young women does not include a great emphasis on organised exercise activity, with sporting participation amongst young women generally declining throughout the teenage years. In contrast, all the young men were involved in exercise, with some greatly involved in team sports. Miller et al. (1993) argue that male embodiment involves expressing bodily power and strength through physical activity, and they believe that masculinity in Western society is learned primarily through organised sport.

The authors found a very different attitude towards eating, and a difference in eating habits, between young women and men. The young women were found not to eat as much, and not to eat with the same enjoyment as the young men. Miller et al. (1993) point to differential societal expectations about body image and shape, with an emphasis on slimness for girls, which make it harder for girls with cystic fibrosis to eat large amounts of food. They found that for young women, attractiveness was equated with slenderness, whereas for young men, being well-built and muscular was important. This supports the research on gendered embodiment discussed in the previous chapter.

The respondents in Miller et al.'s (1993) study had taken on the self-management of their treatment, mostly starting at about 14 years of age. All of the young women in the study reported stopping physiotherapy for varying lengths of time, whereas if the young men stopped physiotherapy it was replaced with exercise. The young women had all had a period of total non-compliance with treatment, whereas none of the young men reported such an episode. Miller et al. (1993) found this to be a contradiction, in that the young women expressed greater concern about their health than the men. However the young men appeared to have a greater sense of control over their health and their lives, with an increased desire to invest in the future, which the authors suggest may be the result of the social practice of masculinity. In addition, the young men expressed less willingness to incorporate cystic fibrosis into their social identities than did the young women. Power and control are key issues in chronic illness management, and the authors postulate that the social construction of masculinity and femininity may impact on management.
Although this was only a small qualitative study interviewing six young women and six young men, it highlights some key issues in relation to the management of chronic illness. Power and control are very important in terms of conditions such as asthma and diabetes which require high levels of 'guided' self-management, particularly when young people are often expected to manage their regime independently by health professionals (Baum and Kinmouth 1985). Miller et al.'s (1993) study also illustrates how gender role expectations impact differentially on young women and men, and how this in turn may affect self-management.

3.2.2 Asthma, Diabetes and Compliance

Klingelhofer (1987) believes that characteristics of asthma make it a particularly fertile ground for non-compliance, in that it is a chronic condition that has a tendency to go into long periods of remission, the treatment regimes are often complex and frequently demonstrate no immediate impact, and the inhaled medication devices can be difficult to use and are conspicuous. He further states that: 'compliance with medical regimens is as poor or poorer in childhood asthma than it is for other chronic illnesses' (1987: 244).

Maintenance of interest can also be a problem for people with asthma. Studies often indicate that an initial improvement in compliance with drug regimes and altered lifestyles can be achieved with improved education, but long-term effects have not been maintained. Tettersell's survey (1993) assessing the compliance of 100 adults with moderate to severe asthma found that 39% did not take their treatment as prescribed, although there were no significant statistical differences relating to gender for any of the correlates. She found that almost half of the respondents were reluctant to use their inhalers in public, and these were mainly the poorest compliers. Although she did not obtain data on attitudes to asthma, she postulates that this reluctance could be related to feelings of stigma.

MORI research (1991) on young people with asthma found that both their knowledge about their condition and their management skills were poor, with confusion about the function of different medications. The researchers felt that this was related to many young people accepting treatment without questioning it or discussing it with their doctor, which they blamed on the fact that most were still accompanied to the GP by their mothers. The report concluded that there was overwhelming support for a clinic aimed specifically at young people. When investigating a cluster of deaths of adolescents from asthma, Birkhead et al. (1989) found that those who died had been responsible for regulating their own medication, noting that there was a lack of appreciation of the severity of their asthma by the
patients' families. These findings are similar to those of MORI (1991), who stated that most respondents were optimistic about their condition, describing their asthma as mild to moderate, although the researchers felt that it could be classified as severe, or moderate-to-severe.

Sibbald et al. (1988) also found younger patients to feel more self-confident about managing future asthma attacks than older patients (age range 15-67 years), but they state that this self-confidence may be misplaced. Delay in people changing their treatment and in seeking help during attacks has been shown to contribute to avoidable deaths from asthma (Brewis 1991). In a further study assessing the theoretical ability of parents and adults to manage an attack of asthma Sibbald (1989) found that many made serious errors, and were not able to recognise potentially life-threatening situations. Fletcher (1991) believes that the combination of decreasing parental supervision and a lack of effective self-management skills may place the young person with asthma at increased risk of severe attacks.

In their qualitative study of adults with asthma, Adams et al. (1997) found that respondents' attitudes to medication and to the meaning of medication were closely related to whether or not they accepted the identity of 'asthmatic'. They identified three main groups in terms of attitudes to asthma, and hence to medication. Firstly, Adams et al. (1997) identified a large group of 'deniers/distancers', who felt that they did not have asthma. These people all used their reliever inhalers, but none of them used the preventer inhalers which they had been prescribed. The next group were 'accepters' who all freely admitted to having asthma, using both their preventer and their reliever inhalers. The smallest group were the 'pragmatists' who were closer to the 'accepters', but who had a selective policy of disclosure. These people used both their reliever and their preventer inhalers, although not always in the 'medically approved' way.

In relation to diabetes and 'compliance', Peyrot et al. (1987) state that the complex nature of diabetes self-management makes it a difficult regime to manage well. Hanson et al. (1987) found age to predict effective self-management of diabetes in adolescence, with older adolescents less likely than younger adolescents to manage all aspects of their diabetes effectively, although they argue that length of time since diagnosis may confound this. Mason (1985) followed up people with newly diagnosed diabetes for one year, and found them to be unsure about vitally important practical aspects of management. She also found uncertainty amongst people about the degree of responsibility being given to them, and poor communication between doctors and patients, leading to many unanswered questions and poor compliance.
In one of the few studies of people with diabetes which takes a qualitative approach, Kyngas and Hentinen (1995) interviewed 51 young people in Finland aged 13-17 years, with a disease duration of over one year. They found a major feature of compliance for this age group to be that the aims should be achievable and meaningful for young people. Their research results support those of Anderson et al. (1988), who concluded that the personal meaning of having diabetes was strongly related to self-care, and to the degree of social and psychological adaptation to the disease. Kyngas and Hentinen (1995) found that the young people with 'good compliance' felt that as a result of good self-care they would achieve worthwhile aims, whereas those in the 'imposed compliance' group felt self-care to have only negative meanings. The young people in the 'non-compliance' or 'conscious non-compliance' groups stated that the goals which they most valued, such as the chance to live freely like their friends, could only be achieved by non-compliance with their treatment. The authors conclude that educational packages should be based on individual need, rather than reliance on a package deemed suitable for all ages.

An additional problem for people with diabetes in relation to knowledge and management skills is that self-management can be carried out perfectly, but an individual may still develop serious complications. As Hopper states: 'the disease has a 'capricious' quality, which lies beyond the domain of human intervention' (1981:15), and this can lead to feelings of frustration and lack of control.

This section has explored the concept of compliance, focusing particularly on young people with asthma or diabetes. Many of the studies on compliance are written from a biomedical perspective, so the solutions proposed may not be seen as relevant by people with a chronic illness. There is little research which explores the effect of gender on the meanings of compliance, and the proposed research aims to examine this issue from the perspective of young people and their mothers.

3.3 Gendered Identities and Chronic Illness

The management of a chronic illness relates to the meanings that the illness has for an individual, and this research will explore gendered meanings in particular. This section will highlight those aspects which may be pertinent to asthma and diabetes. Firstly, key studies which explore the meanings of illness in childhood will be discussed, as these may help illuminate the meanings and subsequent management in adolescence. The section will then discuss research which relates to young people and adults, before focusing on the meanings of stigma.
The notion of identities in this thesis is based on the work of Mead (1961), who identified the dialectic relationship between the 'I', or the 'self', and the 'me', which is the self as seen by others in the social context. Mead (1961) likened this to seeing oneself through the 'looking glass' of the reactions of others, and this symbolic interactionist approach recognises individuals as actively creating their identities. In line with other authors (Charmaz 1995; Adams et al. 1997), in this thesis the 'I' relates to 'personal identities', and the 'me' relates to 'social identities'. It is recognised that individuals do not have just one personal or social identity, but many identities which need to be reconciled with each other.

3.3.1 Childhood

Prout (1989) noted the differential effect that sickness had on 11 year old girls and boys because of their different kinds of friendship networks, and the different meanings of friendship. The boys often found illness a more isolating and threatening experience, because their absence from school could lead to a loss of status or position within the informal hierarchies operating within the class. For the girls however, sickness meant something quite different, with different consequences. When girls were sick, the 'best friend' group was mobilised, and visits were usually made to the home. Thus girls were not separated from their friends to the same extent, but in contrast, sometimes became the focus of intensified friendships. Girls were missed because of their personal characteristics, as opposed to boys, who were only missed, if at all, for their ability to fill a 'position' unrelated to their person, such as one in a football team. Prout (1989) draws on the work of Graham (1984) when he says: 'Rather than sickness being symbolically dangerous, it appears more as a rehearsal for the emotional labour associated with women's health work' (1989: 353).

Prout also noted the accusation of 'skiving' which greeted almost every boy, but rarely a girl, on their return to school, stating:

..it underlined a basic feature of the boys' culture, that being physically fit and tough was highly valued and that sickness, and resort to it as a means of avoiding demands, was a stigmatising form of weakness and incompetence (1989: 350).

In an earlier paper Prout (1986) discusses the ways in which children develop 'stoicism', defined as saying that one is not 'really' sick. He cites previous research (Campbell 1978) which suggests that stoicism is more likely to be expressed by boys than by girls, by older rather than younger children, and by middle-class as opposed to working-class children. In his research on 11 year olds, Prout found teachers often used the term 'wet', particularly in
relation to girls, to indicate: 'a sense of being unable or unwilling to face up to the assumed rigours of an instrumental, demanding and competitive world' (1986: 120). Consequently the boys' claims to sickness were more likely to be believed than the girls, and this tied in with boys' participation in sport, which was used by both boys and their teachers as an index for their proper maleness: 'Normal' boys were judged against stereotypes of toughness and fitness and this overlapped with the concern with wetness' (1986: 125).

Prout concludes:

Wetness was seen as a primarily female characteristic, natural and to be expected in them. It was this that differentiated the interpretation of girls' and boys' claims on sickness. For the former it tended to be seen as an exemplification of their nature whilst for the latter it was, when detected, seen as a threat to their successful transition into being proper men (1986: 131).

James (1993) proposes that personhood is constructed mainly through children's encounters with each other, by 'testing', negotiating and reconstructing stereotypes of personhood. In relation to illness, she found that the 'spoiled identities' of children with chronic disease such as asthma could jeopardise their making and sustaining of relationships. However, Hepper et al. (1996) argue that in relation to asthma, James may have over emphasised the extent to which the potential stigma associated with diseases such as asthma impacts on social interactions, or on children's social identities. One focus of their research was Hamed, a young boy with asthma, and the ways in which he managed to actively and skillfully negotiate a healthy identity, despite having to take regular asthma medication. Although the focus of their study was not on gender issues, it is of interest to note that sportmanship was a major factor in counteracting the 'spoiling' of Hamed's identity, and much of his time was taken up with maintaining his reputation in this area.

3.3.2 Adults

For many people a central theme in managing chronic illness is the concept of control over the self - this does not necessarily mean control in the medical sense, but refers to control over one's personal identities and social identities as a healthy person. Charmaz (1991) believes that people with a chronic illness often try to keep the condition outside the boundaries of their self-concepts by keeping it at the margins of their lives, stating:

..having a chronic illness means more than learning to live with it. It means struggling to maintain control over the defining images of self and over one's life (1991: 5).
Although Adams et al. (1997) agree with Charmaz's (1991) suggestion that chronic illness might lead to a 'diminished self', they found that in relation to the adults with asthma whom they interviewed, this only occurred if an individual could not reconcile the social identity of 'asthmatic' with their other social and personal identities.

In examining the relationships that adults have with asthma, Benner et al. describe one category as 'non-acceptance', which they define as:

...an either extremely objective or extremely subjective view of the disease as external to the self, or in the mind and thus controllable by the mind. For some, non-acceptance means that little space is given to the illness (1994: 230).

Adams et al. also identified one group of respondents with asthma as 'deniers', stating that they: 'experienced damage to the self through their efforts at concealment and denial' (1997: 199). The words non-acceptance or denial often have negative connotations, and in relation to chronic illness, and indeed, more generally, it is often implied that acceptance of a disease or condition is preferable. However, Charmaz states:

Definitions of illness may merge with beliefs about the power of personal motivation, and in turn, these beliefs may be judged as denial....to the extent that people do not experience their altered bodies in their own worlds or to the extent that they can define impairment as temporary, they will not view their conditions as chronic. Their stance looks like denial, but it derives from the reality of their experience (1991: 20).

This is helpful in understanding 'masculine' ways of dealing with chronic illness, as men may for a variety of reasons have more to gain from adopting a 'denial' type approach to chronic illness. Charmaz (1995) explored men's ways of dealing with chronic illnesses which included 'lived-with' conditions such as multiple sclerosis, and 'mortal' conditions such as heart attacks. She believes that there are two essential properties in relation to men's experience of chronic illness. Firstly, illness can threaten masculine identities and lead to identity dilemmas, and secondly, these dilemmas can be recurrent and chronic. She states that identity dilemmas for men revolve around various oppositions, such as: active versus passive; independent versus dependent; autonomy versus loss of control; public versus private self; and domination versus subordination. In addition, Charmaz states:

Chronic illness can undermine all the taken-for-granted identities that support and sustain a man's place in the gender order, including his place in the male dominance hierarchy among men....hence, illness can reduce a man's status in masculine hierarchies, shift his power relations with women, and raise his
self-doubts about masculinity. Consequently, chronic illness can relegate a man to a position of "marginalized" masculinity in the gender order (1995: 268).

Charmaz interviewed middle-aged men, but it seems that the identity dilemmas may be as great - if not greater - for young men with a chronic illness. Charmaz found that one way in which the men she interviewed accommodated to the uncertainty caused by illness was to 'bracket' it, which she defines as 'setting this event apart by putting a frame around it and treating it as something separate and removed from the flow of life' (1995: 272). In this way, the impact of the illness on identity was lessened, with any illness episodes seen as episodic 'flareups and crises'. However, she found that bracketing also raised identity dilemmas in the form of either trying to maintain past identity with a cost to health, or taking illness into account with a consequent risk to personal and social identity.

Although bracketing can reduce awareness of uncertainty, Charmaz (1995) questions why men who must be at least partly aware of uncertainty, do not make lifestyle changes. She states that these men may have given up trying to change, and may have decided to live on their own terms for whatever time is left. Men in this group did not envisage themselves becoming disabled, but either remaining the same or dying. Charmaz (1995) also notes how men can use uncertainty to keep hold of power and privilege in their homes. She found that wives who tried to cajole partners received responses such as: 'Why should I care what I eat? I'm going to die anyway' (1995: 273). Charmaz found that some men attempted to reclaim their past selves, the selves they had been before the illness:

For these men, their "real" selves are and must be only the past self. They lapse into invalidism and despondency if they cannot recapture their past selves (1995: 279).

Charmaz (1995) describes how the men she interviewed (age range 21-85 years) saw their conditions in four main ways, as an enemy, an ally, an intrusive presence and as an opportunity, although conflicting views could be held by the same person. However, some of the middle-aged and younger interviewees took years to reconcile the identity dilemmas that illness placed on them. Drawing on Goffman's work (1963), Charmaz states that viewing one's illness as an enemy both objectifies and externalises it, thus distancing and separating it from personal, if not from social identities. Illness viewed as an intrusive presence places it within the body as an unwelcome occupant that has insidiously become part of self.
In his qualitative study of men aged 16 years and over with chronic asthma, Hewett (1994) noted how many of the men stressed that there was little that they could not do as a result of their asthma, and how: 'on almost every occasion that I asked about the effects asthma might have had on the men's spare or leisure time, conversation turned to sport' (1994: 27). Hewett (1994) believes that this is related to those interviewed being male, and their wish to appear before a male interviewer in a fit and positive light. However, it also appears to relate to gendered styles of illness management.

In research on living long-term with multiple sclerosis, the self-concepts of men were found to change more negatively over time than those of women (Brooks and Matson 1982). Perhaps as complications occur, or the disease becomes harder to manage, men may be more affected because of their desire for good control, and the increasing difficulty of keeping the illness out of their personal and social identities. Charmaz highlights the ways in which the social construction of masculinities can be both beneficial and problematic in terms of illness management, stating:

Traditional assumptions of male identity, including an active, problem-solving stance, emphasis on personal power and autonomy, and bravery in the face of danger create a two-edged sword for men with chronic illness. On the one hand, these assumptions encourage men to take risks, to be active, and to try to recover, which certainly can prompt re-creating a valued life after serious episodes of illness and therefore bolster self-esteem. On the other hand, these assumptions narrow the range of credible behaviours for those who subscribe to them. Hence, they foster rigidity in stance and set the conditions for slipping into depression....an uneasy tension exists between valued identities and disparaged, that is, denigrated or shameful ones (1995: 286).

In contrast, Charmaz (1995) found that women with a chronic illness generally showed more resiliency and resourcefulness than men in preserving aspects of self, even though women were less likely to have spouses to assist them. She argues that this may be because the very nature of 'the self' differs between women and men. Charmaz states:

Women rarely persisted in tying their futures to recapturing their past selves when they defined physical changes as permanent. Quite possibly, women's earlier roles and identities fostered greater adaptability to illness (1995: 280).

Women are often perceived as more able to cope with ill health than men because of the stereotypical expectations of femininities as being adaptive, passive and virtuous (Coppock et al. 1995). However, the social construction of femininities may be both protective and harmful in terms of managing chronic illness; protective, in that it may allow women to be
more adaptable when adjusting to living with chronic illness; and harmful, in the sense that sometimes women may adapt and adjust their lives around illness almost too soon.

3.3.3 Young People

In terms of young people, these gendered ways of managing chronic illness would help explain the findings of Brannen et al. (1994), which seem to conflict with those of Brooks and Matson (1982) cited above. Brannen et al. found that in their survey young men who reported illness generally seemed more optimistic about their health than young women. Among young people with asthma, 18 of the 33 males reported their health as 'good', compared with only four of the 21 females with asthma. It was also found that with respect to asthma and other 'serious' illnesses, more young women than men went to the doctor frequently, with a positive relationship found between the use of primary and secondary health services.

As was previously discussed, in an Australian study interviewing young people with cystic fibrosis, Miller et al. (1993) found gender differences in important areas. In fact, the prognosis for males with cystic fibrosis is better, with a median survival rate of 30 years, compared to 25 years for females, and the authors postulate that this difference is caused partly by different embodiments through the social practices of masculinity and femininity.

Having examined the significance of gendered identities in terms of the effects of chronic illness, this chapter will now explore the meanings of stigma, particularly in relation to the ways in which it affects the management of chronic illness.

3.3.4 Stigma

Goffman (1963) maintained that all stigmatised people wish to hide away their shameful marks, and that a stigmatising attribute is something a person either has or does not have. Since then studies have suggested that the concept of stigma is more complex, with some people deliberately 'coming out' with their disabilities, and others unsure from one day to the next as to whether or not they have a stigmatising attribute (Armstrong 1994). It may also be that the concept of stigma needs to be refined to incorporate a gender perspective. This section firstly considers some general issues in relation to stigma, before focusing on stigma in terms of asthma and diabetes.

Goffman (1963) described a variety of coping strategies which related mainly to whether or not the stigma was obvious to others (discrediting), or could be hidden from others
Someone with a discreditable condition such as diabetes or asthma has the option of trying to hide it, and the two main coping strategies that Goffman highlighted in this situation are described by Armstrong as follows:

Passing: a person with a discreditable stigma can try and pass as 'normal'. Depending on the medical problem this will often require various forms of subterfuge, with the constant risk of exposure. This threat of disclosure and possible shame can be a constant source of psychological tension.

Withdrawal: the avoidance of difficult social situations can be taken further by deliberately withdrawing from social life. In this way the stigmatized avoid all contacts that might produce embarrassment or shame (1994: 68).

Conrad states that: 'the consideration of stigma allows us to confront directly the meaning of illness' (1987: 2). He believes that most chronic illnesses can be potentially stigmatising with personal competence and interactive capacity called into question, creating the possibility of being seen as - or seeing oneself as - less than a whole person. Although illness may be potentially stigmatising, Conrad (1987) believes that stigmatisation is not necessarily a universal experience, and may vary with factors such as family reaction. Conrad (1987) also comments that the connections between stigma potential, perceived stigma and management strategies have been made only for overtly stigmatising illnesses such as epilepsy, although he believes that these connections could be made for less overtly stigmatising illnesses such as asthma. In their study of epilepsy, Scambler and Hopkins (1986) made a distinction between 'felt' (self-maintained) and 'enacted' (experienced from others) stigma, stating that it was the felt stigma that disrupted patients' lives.

In research which examined the ways in which women and men (aged over 21 years) managed chronic illness, Charmaz (1991) highlights the importance of self-presentation. She found that the younger people in her study talked more about their appearances, and that concern with appearance relied on keeping the illness contained, controlling it, and 'passing'. However, it may be that ways of managing such as 'passing' are gendered because they relate to the meanings of illness, which are also gendered. Charmaz draws attention to the risky nature of 'passing', stating that: 'Successful passing often requires an alert assistant' (1991: 69). The need for an 'alert assistant' will be explored in the proposed research, particularly in terms of whether this need relates to the gender of the young person.

Becker et al. (1993) believe the individual's vulnerability to stigma and blame for unpredictable episodes of asthma is reinforced by current biomedical ideologies emphasising self-reliance in the management of chronic illness. They also state that the widespread belief
that asthma is 'all in a person's head' can have serious implications. Becker et al. (1993) describe the dilemma faced by individuals with asthma in knowing when to attend for emergency treatment. Failure to attend early enough may cause the individual to be labelled non-compliant, but they may also experience stigma if they attend for treatment too early, their opinion being discounted if they are not judged to be in need of emergency care.

In a large survey of children and young people with asthma (Action Asthma 1993), feelings of embarrassment and being different from other people were more widely expressed by older children (12-17 years), than those who were younger. Nocon and Booth (1990) also found that respondents in their study of 32 children and 18 adults with asthma expressed embarrassment at having to use their inhaler in public. In a qualitative study of 46 young people aged 13-16 years with asthma, about 50% expressed embarrassment about taking medication in public, saying that strangers stared at them or asked questions (MORI 1991).

Snadden and Brown (1991) used a combination of questionnaires and in-depth interviews to examine the feelings of stigma in people with asthma. Questionnaires were sent to 27 patients who fitted the study inclusion criteria. Eighteen questionnaires were returned (66.6%) from 10 males (55%) and eight females (45%). From the questionnaire they found stigma to be a 'frequent finding' (33.3% of sample), and that there was a positive association between feelings of stigma and frequency of inhaler use which was 'almost exclusively' confined to males. However, follow-up qualitative interviews led the researchers to state that:

..some of the participants showed no effects of stigma at all, while some were concerned that their condition might be mistaken for a different, undesirable or stigmatising condition (1991: 333).

The authors concluded that stigma was not a major theme in respondents' experience of asthma, and that it seemed less important than current literature suggested. There appears to be a conflict in the literature about the effect of stigma on those with asthma, and it could be that factors such as the increasing number of young people with asthma may serve to reduce the stigmatising effect amongst this particular age group.

There are a number of issues which relate specifically to diabetes and stigma. In a wide ranging study of adults, Hopper (1981) found that people with diabetes encounter stigma in relation to marriage and career planning because of potential future health problems, and because they are more likely to be unemployed, which is stigmatising in itself. She also highlights the stigma of transmission to children, as people with diabetes face an increased
risk of their children developing diabetes. Hopper (1981) also found that the increased risk of impotence in men with diabetes resulted in feelings of stigma.

The proposed research will explore the extent to which stigma impacts on the management of asthma and diabetes, and whether the concept of stigma is gendered.

3.4 Conclusions

This chapter has explored factors which may affect 'guided' self-management by young people with a chronic illness. Self-management has been problematised, and it was stated that power and control tend to rest with health professionals, who dictate the parameters of management. This may lead to feelings of disempowerment in young people with chronic illness, causing problems with 'compliance' and consequent blame and guilt. This may be more acute in young people who, because of their age, may be seen as less competent, and who are also less likely to be able to develop a more equal 'doctor-patient' relationship. This research will explore gender differences in the extent to which young people feel able to negotiate ways of self-managing.

The chapter has examined the emergence and meanings of self-help and self-care, and how these impact on the moral meanings of illness. The meanings of chronic illness have been discussed, particularly in terms of the effect of gender. Much of the research reviewed has focused on the experiences of young children or people in middle age, whereas this research will explore these gendered meanings in terms of young people. Few studies have interviewed young people themselves in depth, and even fewer have interviewed parents and young people. Central to this are the different meanings illness has in terms of its impact on gendered identities, and conversely, the impact of gendered identities on the experience of illness.

The concepts of stigma and compliance have been explored in terms of the ways in which they impact on chronic illness management. Studies indicate that there may be a wide variety of reasons for poor adherence to therapy in young people with asthma and diabetes. However, much of this research follows the biomedical model, and a sociological perspective may be particularly valuable in exploring these issues further. The concept of stigma will be explored to assess the extent to which it impacts on the management of asthma or diabetes, and whether it operates in gendered ways. The need for an 'alert assistant' (Charmaz 1991) will be explored, including whether this need relates to the gender of the young person.
Chapter Four

MOTHERS AND CARING

This chapter provides a review of some of the key aspects of the extensive literature on mothers and caring which are relevant to this research. Firstly, it will discuss some of the main arguments for the link between caring and women, and how this relates to femininities. This will be drawn on to help explore and explain the roles that mothers and fathers play in relation to caring for young people with a chronic illness. The chapter will then clarify the concepts that will be used in exploring the caring work performed by mothers when they negotiate self-management with young people who have asthma or diabetes. The ways in which mothers may affect the formation of gendered attitudes to self-management will be explored, as will the effects that the gender of the child may have on mothers' care-giving. A key focus of the proposed research will be the differential effects that caring for young women and young men can have on mothers.

Of particular relevance to mothers of young people, especially those with a chronic illness, are the problems that can arise from the conflict of the 'responsibility versus autonomy' dilemma described by Silverman (1987b). He states that parents are expected to balance the conflicting norms of being held ultimately responsible for their child, with respecting the young person's autonomy and ability to self-manage. The consequences of this dilemma for mothers will be explored, as will the role that mothers play as mediators on behalf of their children.

4.1 Caring - Naturally Women's Work?

Although many people have attempted to define caring, it has not proved an easy task, leading to a confusion of definitions and ideologies. Graham states very succinctly that:

...in broad terms, it is a concept encompassing that range of human experiences which have to do with feeling concern for, and taking charge of, the well-being of others (1983: 13).

She sees caring as having two components, labour and love, and being associated on the whole with women. Anderson supports this, stating:

For the most part, it is the women in the family who take on the responsibility of caretaking and are expected to do so without financial
remuneration and, in some instances, without adequate resources or knowledge of the resources that are available to them (1990: 79).

There is a large amount of literature on the relationship between women and caring, and some of its central themes will now be discussed. Caring is often seen as the key concept delineating one of the major differences between female and male, that of 'being' versus that of 'doing' (Chodorow 1978). 'Being' encapsulates what is seen as the essentially passive nature of femininity, as opposed to 'doing', which is seen as the self-directed and active nature of masculinity. Nancy Chodorow's (1978) influential objects relation theory was set within the socialisation perspective, and argued that the caring role is reproduced by mothers themselves, who by caring for sons and daughters in different ways recreate the personality types associated with masculinity and femininity.

This early work of Chodorow (1978) and other proponents of the objects relation theory tended to present a universalised account of femininity and masculinity which left little room for variation. The reproduction of gender was seen to be produced through the mother-child relationship, with the child's sense of gender identity being developed between the ages of 18-36 months. Boys' patterns of identification and individuation were seen to result in the development of a concept of self which denied intimacy and connection in relationships. In contrast, girls individuation patterns involved identification with their mothers, and consequently with the roles of their mothers, which included seeing women as the satisfier of the needs of others, the denial of women's personal needs, and a lack of autonomy for women (Wilkins 1993). Chodorow argued that ultimately, this could lead to women's: 'loss of self in overwhelming responsibility for and connection with others' (1978: 59).

Gilligan's (1982) influential research used the work of Chodorow (1978) and others to argue that early socialisation leads girls to develop a strong sense of moral caring in relation to others. In her later work on middle-class American girls, Gilligan (1990) found that as girls moved into adolescence, they changed from being outspoken and sure of themselves to becoming more conforming and hesitant. Gilligan (1990) concludes that this is due to girls realising that to become 'good women' they must become more selfless.

The socialisation perspective has been criticised for being overly deterministic, ignoring both the economic and social relations which have contributed to the social construction of the caring role (Graham 1983). Segal (1987) argues that focusing only on pre-Oedipal attachment ignores all of the social practices which separate girls from boys. by which boys develop a sense of themselves. She states that:
The fears which will accompany the boy's struggle to distance himself from his mother - often with her encouragement and assistance - have many positive compensations. They are compensations which will continue to privilege him in relation to women throughout his life (1987: 153).

Morgan comments that although the commitments of women seem natural, this sense of naturalness develops from broader, more pervasive notions of care, reciprocity and human nature. He states:

..issues to do with caring, therefore, point to the ways in which deeper social and ethical issues are mobilised and shaped in particular historical contexts and given meaning in particular institutions and sets of gendered relationships (1996: 110).

Ungerson (1983a) also argues that women rather than men predominate amongst informal carers because there are powerful ideological and material forces operating to ensure that they will do so. Graham (1983) states that the concept of dependency has a very different meaning for men and women, and that it cannot be understood in isolation from the sex-gender system. She believes that for women their dependent status - as housewives, mothers and dutiful daughters - is conditional upon their being depended on by others. This means that for many women being a dependent means giving care, not receiving it, and Graham states that: 'caring defines both the identity and the activity of women in Western society' (1983: 30).

Segal (1987) also states that the strong sense of caring found in women is merely a function of their subordinate position, and in fact serves to perpetuate this. She argues:

Perhaps this moral sensibility would disappear, for instance, if women were as socially valued and privileged as men. It is well known that those with less social power and confidence are more likely to develop a greater attentiveness, watchfulness, and desire to please in their relations with others (1987: 148).

Segal (1987) believes that this failure to examine alternative connections between women's 'special' qualities and women's subordination becomes a particular problem when looking at the literature on mothering. She claims that much of this work has an exaggerated focus on the differences between women and men, with a disregard for the ways in which social practices affect gender identity, arguing that this has led to an idealisation of 'maternal' and 'feminine' ways of behaving. As Oakley states:
Men's potential to be active and involved fathers is not in question; what is in question is why so few of them assume this commitment... (1986: 90).

This section has examined some of the different perspectives which link caring with women. Although it is assumed that in most cases, mothers will be interviewed as the main parent involved in helping their child manage asthma or diabetes, the role of fathers will also be examined through the interviews with young people and mothers. By exploring the roles that mothers and fathers play in relation to caring for young people, and the ways in which teenage girls and boys are cared for, and care for themselves, the proposed study aims to add to research which examines how caring is socially constructed as women's work.

The following sections will focus on two conceptualisations of caring. The first was proposed by James (1992) and has proved useful in research on caring, and the second is a relatively new conceptualisation of caring proposed by Mason (1996), which seems particularly pertinent to the proposed research.

James' (1992) research compared women's domestic carework with that of hospice nurses, using a conceptualisation of caring as emotional labour, physical labour and organisation. She particularly draws attention to the organisational skills involved in balancing physical and emotional labour. Duncombe and Marsden (1995) believe that James' model unites the social structural and socialisation perspectives, whilst avoiding the pitfalls of functionalism and biologism. The three aspects of caring within her conceptualisation will be discussed, drawing on the work of others to illustrate specific themes.

4.1.1 Emotional Labour

It is only since the 1980s that the importance of emotional labour has been acknowledged. James states that 'emotional labour is most easily recognised as part of the caring role of women in the home' (1989: 22). She believes that it has remained unrecognised for so long because it involves both women and 'emotion', and is consequently seen as 'natural', unskilled women's work. In addition, James (1989) states that when acknowledged, 'emotion' and 'feelings' are seen solely as a part of mothering and caring, and not as a major factor in social regulation.

Duncombe and Marsden (1993) state that Parsons' (Parsons and Bales 1956) functionalist discussion of the ideal nuclear family was based on the gender division of emotions. This contrasted clearly the instrumental view of men earning money in the public sphere of work, with women responsible for providing emotional stability and warmth in
the private domestic sphere. In effect, the gendered division of labour resulted in the
gendered division of emotions.

There are various definitions of emotional labour, although all make conceptual links
between care, feelings and emotions (Smith 1992). Hochschild defines emotional labour as:

..the management of feeling to create a publicly observable facial and bodily
display, in order to sustain the outward countenance that produces the proper

She distinguishes between emotional labour which is sold for a wage and has exchange
value, and emotional work/management which is done in a private context and has use
value. James (1989) defines emotional labour as the labour involved in dealing with other
people's feelings, a core component being the regulation, or management of emotions. She
states that:

..to be effective, the 'labourer's' skills must include firstly, being able to
understand and interpret the needs of others, secondly, being able to provide
a personal response to these needs, thirdly, being able to juggle the delicate
balance of each individual and of that individual within a group, and
fourthly, being able to pace the work, taking into account other
responsibilities (1989: 26).

There is little research on the emotional labour of mothers in relation to young people. It
may be that some aspects of the 'worrying' which Brannen et al. (1994) found that mothers
of teenage children engaged in could be seen as emotional labour, but the term was not used
explicitly. However, the concept of emotional labour does not seem to adequately describe
all the aspects of what the mothers in Brannen et al.'s (1994) study were doing, and thus
runs the risk of making some of the work invisible. This aspect of Brannen et al.'s (1994)
study is discussed in more detail later in this chapter.

4.1.2 Physical Labour

As more women join the labour market Duncombe and Marsden (1995) postulate that a more
equal division of housework and the physical tasks of childcare might emerge, as these tasks
become more visible. However, they comment that in reality many men neither see the need
for such work or feel responsible for it, except in cases where their wives employment
brings in a substantial wage (Robinson 1988). This, combined with women's continuing
emotional responsibility leads Duncombe and Marsden to conclude that women in paid
employment must continue to perform a triple shift, including both the double shift of
housework and paid work, plus the emotional work needed to keep family members happy. Brannen and Moss (1991) talk in terms of a 'stalled revolution', and draw on the work of Hochschild, who states:

In the last forty years, many women have made a historic shift, into the economy. Now it is time for a whole generation of men to make a second historic shift - into work at home (1989: 238).

Brannen and Moss argue that this will require a change in ideas about work, childhood, parenthood, and family life, and a recognition of: 'existing dominant ideologies and of their inappropriateness and potential for damage' (1991: 261). The proposed research will examine the extra physical work that may be involved in caring for a young person with asthma or diabetes.

4.1.3 Organising Care

James (1992) states that to the daily givers and receivers of care, organisation is probably the least obvious of her three components of care, because of its invisibility. However, she believes it to be the link between how the balance of emotional to physical labour is developed and maintained. She draws attention to the fact that domestic arrangements have to be flexible enough to accommodate sudden crises, and highlights the fact that it is usually women who arrange their paid work so that it fits around family work. Brannen et al. (1994) also found that most of the mothers in their study felt that they had fitted paid employment around their families.

James (1992) claims that although the person cared for may be able to negotiate their requirements, responsibility for planning and co-ordinating remains with the carer. This seems to restrict the receiver of care to a rather passive role, as there may be situations where the 'receiver' of care is also responsible for planning and co-ordinating care. However, in contrast to carers in hospital, James (1992) argues that the responsibility for care does not necessarily give domestic carers power. She cites the work of Ungerson (1987), who comments that not only are carers subject to the comings and goings of others, but that they may also be coerced into a 'caring relationship' in which there is little room for negotiation, and little satisfaction.

James' (1992) conceptualisation of caring has been influential, and using it in the proposed research would enable many aspects of caring to be explored. However, there appear to be limitations, particularly in relation to the concept of emotional labour, which
may be too general to allow the specific work of mothers to be fully explored. Her conceptualisation also allows the receiver of care only a limited, passive role.

Mason (1996) has recently developed a conceptualisation of care which relates specifically to care for family and kin, and which allows more detailed exploration and recognition of the various aspects of caring which would be subsumed under James' (1992) overarching concept of emotional labour. Mason (1996) sees care as a multi-dimensional activity that is relational, involving morality, feeling and thought, and she proposes various ways in which these dimensions could be conceptualised around family and kin relationships. She rejects the idea of carers necessarily being women, although she recognises that they often are. Drawing on the work of Stanley and Wise (1993), Mason (1996) suggests that we should reject binary notions of the self and its relationship with the body, mind and emotions, and following the work of Sevenhuijsen (1993), she states that labour and love should no longer be thought of as a dichotomous relationship. Instead, she introduces two new interconnected concepts to specifically frame the thinking and feeling around care, rather than seeing these as merely 'by-products' or 'motivational states of mind'.

4.1.4 Sentient Activity

'Sentient activity' refers to thinking and feeling as skilled activities in relation to care and responsibility for family and kin. Mason (1996) gives examples such as attending to or interpreting the needs of specific others, and organising or thinking through relationships between oneself and others. In contrast to Graham's (1983) definition of care used at the beginning of this chapter, Mason (1996) avoids conceptualising sentient activity as either labour or love because she feels that this leads to unhelpful dichotomous distinctions between feeling states and activities. In addition, this avoids judgements being made about the connections between the activities and the nature of one's feelings for the person being cared for. She illustrates how this concept could be used by discussing the work of Brannen et al. (1994), who found that mothers (very rarely fathers) engaged in a great deal of 'worrying' about the well-being and activities of their teenage children. In her own research Mason (1987) found wives took responsibility for overseeing the health of their husbands, and for smoothing their transitions into retirement. Mason (1987) struggled to categorise this work, eventually settling on what she now considers (1996) to be unsatisfactory terms such as 'worry work', and 'mental labour'.

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A further example Mason (1996) draws on which is relevant to this research comes from DeVault's (1991) study of 'feeding' the family. Mason highlights what she would describe as the sentient activities involved in shopping and cooking, such as:

- noticing, interpreting, and responding to the needs of others; juggling dietary requirements and individual preferences; working these into some form of shopping and eating plan often whilst shopping in relation to what provisioning choices are actually on offer; attempting to synchronise the timetables of family members in relation to eating; and orchestrating social relations around mealtimes (1996: 28).

In addition, Mason uses DeVault's (1991) work to draw attention to a key factor, which is the invisibility of this work, stating that:

- when one person takes responsibility for the work [sic], others rarely think about it. Even the one who does it - because so much of her thought about it is never shared - may not be fully aware of all that is involved (1996: 142).

Although Mason (1996) recognises that much care involves heavy physical labour, she believes that an overemphasis on this aspect of caring might mean that both the significance and the 'potentially gruelling' nature of sentient activity are under estimated. This concept appears to be pertinent in terms of the proposed research, where it is not anticipated that mothers will be engaging in particularly hard physical work in terms of care. However, they may be engaged in time consuming, draining and often solitary sentient activity which may well be invisible to others and to mothers themselves. Mason (1996) also states that once sentient activity is seen as skilled activity, there can be an exploration of how the skills are developed. In the research proposed this relates not only to the gendered nature of the activities of parents, but also to the gendered ways in which young people may develop these skills.

4.1.5 Active Sensibility

Mason proposes the concept of active sensibility, which refers to the activity of feeling a responsibility or a commitment to someone else:

I am referring to a relationally and socially constructed 'predisposition' to draw a connection between self and specific others, and to take on a responsibility to care (1996: 31).
Mason (1996) sees these commitments as being actively constructed through negotiations with others, rather than being merely a passive response to a particular set of circumstances or roles. This conceptualisation allows the receiver of care to play a more active role in the negotiation of care, unlike that of James' (1992) conceptualisation of care. Mason draws on her own work with Finch (Finch and Mason 1993), which focused on the negotiation of moral identities between kin rather than on moral feelings, rejecting the theories which suggest that people have 'static inner feelings' or attitudes which direct their activities. Finch and Mason (1993) argue that women do not assume caring responsibilities through an abstract notion of obligation, but instead build up a series of commitments in the life-course of their gendered biographies.

Mason (1996) places her relational approach within a sociology of personal relationships. Consequently she states that these processes cannot underpin the construction of gender differences or gendered moralities, because these sentient skills and active sensibilities are not inevitably or necessarily transferable to other situations, such as caring for other people. Thus an exploration of men's caring is possible within Mason's (1996) conceptualisation, and this may prove useful in terms of the proposed research, which aims to include an examination of the role of fathers in caring. The concept of active sensibility will also be useful when exploring the negotiations which may take place between parents and teenagers during this time of 'transition'.

Mason's (1996) concepts appear to be highly relevant to the research proposed, and they will therefore be used to explore the activities of mothers, fathers and young people in this research. However it is anticipated that there may be some activities which come within a separate category of 'developmental activity', which relate to the role of parents in terms of the ways in which children and young people negotiate independence. Mason's (1996) concepts do not cover this specific type of activity, which will now be discussed.

4.1.6 Developmental Activity

Developmental activity is of particular importance in relation to the development of independence and autonomy in young people. This type of activity was described by Ribbens (1994) in terms of the different meanings she found independence had for the mothers of children who were seven years old at the start of her four year study. Independence could be seen as physical self-care and/or independence of ideas. Ribbens (1994) also found differences relating to mothers' conceptions of what sort of skills were felt to be needed for children to attain independence. These could include physical skills, decision-making skills, a capacity for rationality, and most problematic of all for mothers, a
future orientation. Ribbens (1994) found that dilemmas emerged for mothers around how far to push children, plus the paradox that training for independence could be seen by mothers as another form of time consuming dependency need. She also found that independence was evaluated within different frameworks of meaning by mothers, and consequently mothers' developmental work was orientated around these:

Is independence about increasing freedom to make choices, unrestrained by childhood limitations, protections and incapacities, or is it about increasing responsibility, with the need to be self-reliant in a hard world, such that it entails a loss of freedom from the irresponsibility and protectiveness of childhood? (1994: 181).

Ribbens (1994) states that a further paradox appears at the heart of these ideas about independence, in that valuing independence involves an intrinsic future orientation, yet children are construed as lacking in experience, without the capacity to take a future orientation. These factors were thought by mothers to limit children's ability to know their own best interests, and to be self-determining. As a consequence, she found that many mothers felt children needed training and 'pushing' towards independence, and that there was concern expressed over who should take control of the definitions of children's long term and short term needs for freedom and opportunities. Hockey and James (1993) believe that this perceived lack of future orientation may be the crucial factor seen as separating adults from children. With respect to young people with a chronic illness, the notion of a future orientation is even more important in terms of potential long term complications.

The value of the concept entitled 'developmental activity' will be assessed to see whether it helps identify a particular aspect of the work of mothers, and in turn, how this work relates to mothers' perceived meanings of independence. It will also explore mothers' views on the capacity of young people to take a future orientation, particularly in relation to the management of chronic illness. The ways in which this impacts on developmental activity and the effect that the young person's gender has on the performance of this activity will also be examined.

4.2 The Gendered Care of Mothers

There are two factors about which most of the research on caring agrees. Firstly, that caring is generally associated with women, and secondly, that whilst care-giving can be extensive, stressful and very time-consuming, it is often invisible (Hill and Zimmerman 1995). The proposed research aims to uncover the role that mothers play when young people have a chronic illness. This may be a subtle process of negotiation which becomes visible only
when things go wrong. An equally important focus of the research will be to examine the ways in which the gender of the young person impacts on the care mothers give, and this will be now discussed.

It is surprising that so little research has analysed the effects of the child's gender on the care that mothers give, particularly in relation to illness. One reason may be that much of the feminist research exploring mothering has examined caring from the mother's perspective. In one of the few studies which has explored this issue, Hill and Zimmerman (1995) found that interviews with the mothers of 32 black American children and young people with sickle-cell disease revealed a gender-based pattern of care-giving. Mothers of sons were more likely to perceive their children as sicker, and invested more effort in their care-giving than did mothers of daughters, who described their children as more willing to exercise good judgement and self-care. The increased care-giving for sons was also linked with lower maternal employment rates. However, the young people themselves were not interviewed. The authors felt these findings were surprising, particularly in view of research such as that by Mechanic (1968), who found that boys were more likely than girls to believe that they should react bravely to pain and illness, and expected their mothers to be less brave about illness than their fathers. In their conclusion, Hill and Zimmerman (1995) suggested that their findings could be partly explained by the particular concern felt for the survival of boys which was prevalent in low income, black communities. The proposed research will explore what findings emerge from a sample of young people with asthma or diabetes. In addition, because both mothers and young people will be interviewed, it will be possible to explore the gendered roles that young people themselves play in the negotiation of self-management.

Mothers and fathers can both have gendered expectations in relation to the illness behaviour of their children, although more is known about mothers. For example, when exploring parental reports of children's adjustment to chronic illnesses such as diabetes and asthma, Eiser et al. (1992) found that mothers reported significantly more dependency needs amongst adolescents and females, despite the fact that there were no reported differences in disease severity and consequent restrictions. Brannen et al. (1994) also found that the extent to which illness was reported in young people by either themselves or their parents varied significantly by sex, with young women more likely to report themselves, or be reported by their parents, as ill. Young women were found to be more autonomous in treating their own illnesses as opposed to young men, who were more likely to consult their mothers. although the reasons for this were not explored in any detail.
During interviews with working-class women about concepts of health and illness, Blaxter (1982) found many women to have strong moral views about illness, with a belief in 'mind over matter', a belief that illness could be overcome by strength of character. These views were not usually applied to young children, who were deemed unable to have the capacity or the desire to dramatise or malingering. However, as the children grew older, Blaxter found that mothers began increasingly to judge them by their own standards, but she states:

Rather more notably for girls than for boys, complaints of symptoms might be described as 'moaning and groaning', 'acting up', or just playing on it (1982: 34).

Mayall (1996) highlights the fact that parental understandings of gender impact on the ways in which children are parented. She also draws attention to the difficult and contradictory tasks that mothers are faced with in relation to bringing up sons:

..preparing their sons for a gendered social world, heavily enforced, as at school; and making clear (if they so wish) that such stereotypes do not hold for the home (1996: 68).

Mayall (1996) believes that on balance, it seems that mothers prepare their sons to face the public world, although she states that evidence is lacking on this issue.

In her study of the mothering of young children, Ribbens found gender to cross-cut family unity in ways that are: 'generally completely taken for granted' (1994: 70). However, whilst sharing the same gender was thought to provide the basis for companionship between parent and child, she found that at times there was also the suggestion of something 'special' between a parent and child of the opposite sex, although what this consisted of was left unstated. Ribbens (1994) draws attention to the research of Newson and Newson (1978), which also suggested that there may be a very private aspect of the parent-child relationship, being concerned with a particular warmth and protectiveness in terms of mothers and sons, and fathers and daughters:

..there seems to be a tendency for children to turn to the opposite-sexed parent to express dependency or to solicit indulgence, and to the like-sexed to enjoy more grown-up companionship on an equal level, sometimes with a spice of almost conspiratorial adventure for both the pair (1978: 292).

This 'special' relationship may be significant for the proposed research, as mothers appear more likely than fathers to be involved in caring for children and teenagers with a chronic
illness. Any differences in feelings of protectiveness or dependency may manifest themselves in differences in expectations for self-management.

This section has drawn on the small amount of literature which indicates that parents have gendered expectations in relation to both illness behaviour, and to the care needed by their children. However, little research has been carried out in this area, and in particular, there is a lack of work exploring these gendered expectations from the perspectives of both parents and young people.

4.3 The Effects of Care-Giving on Mothers

Marsden and Abrahams (1987) argue that academic research and discussion about caring has focused mostly on the exploitation of women's labour, rather than on the emotional strain of the caring relationship which women themselves may find more problematic. Thomas (1995) also draws attention to the contradictory effects of domestic labour on the health of women, distinguishing between the contributions of domestic labour to family health, and the effects of doing domestic labour on the health of women.

This final section will focus on three specific ways in which mothers can be affected by care-giving for young people with a chronic illness. Whereas Section 4.1 examined the link between caring and women from a theoretical perspective, this section will focus more on the practical implications that care-giving can have for mothers. Firstly, it will look at the effects that having ultimate responsibility for their child's health may have on mothers, particularly when their child has a chronic illness. Secondly, it will explore the problems posed in balancing the conflicting norms of acting 'responsibly' with respecting the young person's autonomy and ability to self-manage. Thirdly, this section examines the role of mothers in acting as mediators on behalf of their children.

4.3.1 Responsibility for Young People

In relation to the work that women do in generally preparing children for work and adulthood, Hutson and Jenkins state that: 'mothers and fathers, but particularly mothers, cajole, support, comfort, bully, constructively neglect, and push their children into adulthood' (1987: 62). Further, Hughes et al. state that:

..over and above the physical demands and restrictions that mothers face, there is the added burden for most of feeling continually and ultimately responsible for the health, development and happiness of their children (1980: 18).
This sense of responsibility is a central theme running through much of the work on mothers, caring and health. In a large study exploring the inter-relationship between young people (aged 15-17 years), health and family life, Brannen et al. (1994) examined the ways in which parents and young people negotiated changes in responsibilities for health which had been shouldered by parents in earlier years. They found that in practice, power went 'underground' and was exercised covertly, with communication becoming the new mode of control. However, they found considerable differences between mothers and fathers in terms of beliefs and practices relating to parenthood. Mothers emphasised the importance of communicating with young people, and through the 'duty' of worrying were constantly reflecting on their relationship with their daughters and sons. Indeed, Brannen et al. (1994) found worrying to be one of the most gender-differentiated aspects of parenthood, with mothers working very hard at concealing their concern for their teenage children, and more recently Brannen stated that: 'worry was seen as a female weakness to which only mothers were 'prone' ' (1996: 120).

This is supported by Duncombe and Marsden’s (1995) research, in which mothers stated that they felt fathers' relationships with their children lacked 'emotional participation', and the work of Rubin (1983), who found that although contemporary fathers appeared more able than those in previous generations to play with their children, this play did not often include emotional work. In her study Ingham (1984) also found that although men might participate in childcare and domestic tasks more than their fathers did, they still failed to take any deep emotional responsibility for marriage and fatherhood. Further, Duncombe and Marsden (1995) state that men are likely to see women's emotional work with children as unnecessary and debilitating 'fussing'.

Brannen et al.'s study (1994) found that mothers were described as the principle parent responsible for health in most cases, with many mothers concerned that young people did not take sufficient responsibility for their health. Although some young people aged 16 years and over took on more responsibility in relation to their own diet and bodily health, mothers often took back responsibility when illness occurred. Mothers performed illness surveillance covertly, fearing being accused of 'fussing', and mothers were found to worry particularly about 16 year olds because of their recognition of societal expectations that their child should gain independence. Mothers were less likely than fathers to feel successful as parents, and this is supported by the research of Rose and Bruce (1995), who found that whereas caring was perceived as normal and natural for women, it was seen as something special and esteemed when performed by men. Merely to attempt to care was seen as
praiseworthy in a man, whereas for a woman it was seen as her 'natural duty', and was expected to be performed well. Supporting this, Brannen and Moss (1991) found that women accommodated the unequal division of the domestic workload in 'dual earner' partnerships by using a number of strategies which included giving priority to the importance of the emotional support, rather than the limited practical support of their husbands.

The situation is more complex when the young person concerned has a chronic illness that has the capacity to be self-managed, and researchers (eg Burton 1975; Baruch 1981) have highlighted parents' feelings of responsibility in terms of caring for a child with a chronic illness. However, the sensitivity of mothers in particular to any signs of illness in their child is not only of practical benefit, but has a symbolic, moral value (Locker 1981). According to Brannen et al.: 'it constitutes an important criterion of the provision of 'proper care' by which others judge mothers, and hence mothers judge themselves' (1994: 90).

Ungerson (1983b) argues that women can appear to both dictate and uphold the motherhood model, particularly when their child has an illness, thus reinforcing the exclusion of men from important aspects of caring. She cites research by Wilkin (1979), who found that fathers of children with a mental handicap made a relatively low contribution to caring for their child, but when asked, only a small minority of mothers wanted more help with domestic tasks:

Most (mothers) accepted that physical care was something for which they should be responsible and which, in any case, they felt they were better able to do than others (1979: 173).

Ungerson (1983b) states that one consequence of this is that caring comes to be seen predominately as the territory of women, and is conceptualised as such. Anderson and Elfert (1989) also highlight the competence displayed by mothers in relation to the care of children with a chronic illness. They comment that during interviews, mothers often gave the impression that they were the only person involved in an event, whereas fathers had also played a part. They concluded that women took over the care because they saw themselves, and were seen by their spouse, as more competent in managing the child's illness. However, they state that this cannot simply be dismissed as women wanting to take control of the situation. Instead, they argue:

...it should be recognized that not displaying competence carries serious consequences, not only within the context of the family, but also in interactions with health professionals and others in society (1989: 736).
Anderson and Elfert (1989) place this within the context of 'the ideology of competence', which they claim: 'is generated within the larger social organization, legitimized by health care professionals, and, internalized by women, perpetuates the role of women' (1989: 742). They draw on the work of Goldner, who argues that:

...women's socialization sensitizes them to the feelings of others and promotes the notion that caretaking is their responsibility, indeed, perhaps their raison d'être (1985: 41).

In addition, Anderson and Elfert (1989) found that mothers often felt responsible for having 'created' a child with a health problem, and this feeling of responsibility could put their competence into question, leading to feelings of overwhelming guilt and blame. As a consequence, 'displaying competence' took on a heightened importance. In her research on children with diabetes, Lindsay (1985) found that mothers often attempted to blame themselves for their child's illness, searching for a cause particularly in events that had occurred just before the diagnosis. For example, one mother was reported to blame the onset of her son's diabetes on the fact that she had 'thrashed' him two days previously.

This section has examined the effects that feeling ultimately responsible for their child's health can have for mothers, relating it to the 'ideology of competence', which is a key focus of the proposed research. The proposed research will also explore whether the gender of the child has an impact on displays of competence. It may be that the competent mothering of boys is seen as somehow more important than the competent mothering of girls. As Flax (1978) remarked, mothers may 'value' sons more, which reflects the higher social esteem men generally have.

When young people with a chronic illness are involved, achieving 'competent' care can be more complicated because of the responsibility versus autonomy conflict (Silverman 1987b), and this will now be discussed.

4.3.2 Responsibility and Autonomy - An Impossible Dilemma?

When young people have a chronic illness that can be self-managed it appears that mothers can be placed in a difficult position, with various conflicting pressures on them. They are aware of the need for young people to become autonomous in self-management, but mothers are still seen as ultimately responsible for the health of the young person. Somehow they are expected to balance the conflicting norms of acting 'responsibly', with respecting and encouraging the young person's autonomy and ability to self-manage. This conflict was
noted by Silverman (1987b), who drew attention to the potential 'no-win' situation that parents, usually mothers, could be placed in during outpatient consultations.

Health professionals may accentuate the difficult situation that mothers are placed in by adding their conflicting expectations and pressures. As previously discussed, many published studies show that young people with diabetes and asthma often have the poorest adherence and disease control when compared to other age groups (Bobrow et al. 1985; Rainwater 1983; Birkhead et al. 1989). Health professionals frequently suggest that one way of overcoming this is if parents continue to be involved with treatment, although in reality, this usually means mothers. For example, in relation to diabetes Follansbee states that:

..while a shift towards greater responsibility around age 12 does seem warranted, parents do need to remain involved in a supervisory fashion. For example, parents who continue to maintain significant responsibility for overseeing diet and assuring that meals and snacks are eaten on time have children with better metabolic control (1988: 350).

So although health professionals encourage young people to be autonomous in self-management, they can also reinforce the role of women as caretakers, and Anderson and Elfert (1989) draw on Goldner's work, who argues:

..even as we (health professionals) tell mothers to let family members "speak in their own voice" or "not to be so helpful"....we depend on their traditional empathy and ironclad sense of responsibility to get things done. Insofar as a woman's identity is wrapped up in her ability to nurture, she will do almost anything to "fix things" (1985: 41).

However, Silverman (1987b) argues that parents are then faced with another dilemma, in that they are expected to be responsible without 'nagging', which he states can be seen as the 'other side of the coin' to responsibility. In the proposed research the issue of 'nagging' will be explored from the perspective of mothers. Segal (1987) has discussed 'nagging' in terms of the differential power relations between women and men, arguing that:

All power relations enable a more overt expression of aggression from the powerful, while ensuring its greater suppression in the powerless, who may direct their aggression against themselves (accounting in part for the higher levels of depression in women) or express it in relatively powerless ways - such as 'nagging' or self-righteousness (1987: 153).
Maguire (1992) also explores 'nagging' from a power perspective, by examining how power is used against women, and she draws on Lukes' (1975) model of the three 'faces' that power wears. Maguire (1992) describes the third face of power as operating by controlling women's perceptions of themselves, their awareness of reality, and in this way, she argues, the circle of power becomes complete. Maguire states that one of the ways women should experience their strength is by:

..repossessing our language which has long been used against us. For example, what is a nag but a person characterized by her persistence and conviction? (1992: 25).

However, this issue can also be examined in terms of Ribbens' (1994) reconsideration of power in line with meanings and issues relevant to parent-child relations. She uses Rich's (1977) suggestion that the power of women may be found, not in power over others, but in 'transforming power' (1977: 99). Ribbens highlights the possibility that in the private sphere the exercise of power may be seen as indicative of caring, stating:

..the exercise of power might be described as a duty that women are burdened with, which they are obliged to exercise to meet the needs of their children, despite any opposition from their children. Power in this case is being exercised to further the interests of the children, who are subjected to the power, rather than those of the mother, who exercises the power (1994: 207).

Although she draws attention to the fact that there is a presumption that adults can define children's real needs and interests, she states that the exercise of power in these circumstances is similar to the exercise of dutiful responsibility. Similar findings were noted in relation to mothers and food. Charles and Kerr (1987) also found that although women did most of the food shopping and cooking within families, this did not lead to them wielding power in their own interests: 'As providers of food for their families they come to subordinate their own needs and interests to those of their partners and children' (1987: 173).

Parents also run the risk of being accused by health professionals of overprotectiveness, as was highlighted by a recent joint report from the Royal College of Physicians and the British Paediatric Association entitled, 'Alcohol and the Young' (1995). When discussing the need for young people to take responsibility for their own actions, the report states: 'the mollycoddled child grows into the adolescent who cannot work out limits for himself or herself' (1995: 4). This issue of overprotecting, or 'mollycoddling', can be linked to the many psychological studies which still revolve around the idea that parental traits play a role in the development and management of childhood diseases (Mrazek 1989). The mother and
mother-child relationship have been particularly focused on, with terms such as maternal rejection, emotionally controlling, victimising and dominating, restrictive, oppressive and overpossessive being used (Askilden et al. 1993).

The proposed research will extend the work of Silverman (1987b), by exploring how mothers are affected by the dilemma of encouraging autonomy in young people, whilst still being held ultimately responsible for the health of their child. It will also examine to what extent it is mothers who are faced with accusations of 'nagging' or 'mollycoddling', and the impact that this can have.

4.3.3 Mothers As Mediators

The ideology of competence (Anderson and Elfert 1989), combined with the responsibility felt by mothers for young people with a chronic illness, may also impact on the role mothers play in mediating on behalf of their child. Ribbens (1994) states that almost all mothers have to act as mediators because of the way in which children are viewed as 'morally incompetent' in contemporary Western societies. She cites the work of New and David (1985) who suggest that mothers mediating outside the home are trapped between love and understanding for their individual child's views, and pressures on them to make their child conform. Ribbens believes that women may actively negotiate their own understanding of situations, stating:

In particular, a mother may place herself more clearly (1) as advocate/agent acting on behalf of the child to seek other people's understanding and sympathy for the child's point of view, or (2) as representative/agent acting on behalf of wider society to bring the child 'into line' with other people's expectations (1994: 199).

The role that mothers play as mediators for young people with a chronic illness in both public and private settings will be explored, particularly in relation to the ways in which this role impacts on mothers, and the extent to which the mediating role is affected by the gender of the young person.

4.4 Conclusions

This chapter began by examining some of the main arguments which link caring with women. Two important conceptualisations of caring were discussed in detail. James' (1992) conceptualisation appears to restrict the 'receiver' of care to a rather passive role which may not be appropriate in terms of young people with a chronic illness. In addition,
the concept of emotional labour used by James (1992) was not able to fully describe the work of mothers, particularly the 'worrying' which other research indicates may form a large part of their work with teenage children.

Mason's (1996) conceptualisation of care was developed specifically for use with family and kin, and appears to allow a more detailed exploration and recognition of the various aspects of caring which James (1992) would classify as emotional labour. Mason's conceptualisation allows an exploration of the caring roles of both mothers and fathers, and recognises that the 'receiver' of care may play an active role in the negotiation of care. In addition, by seeing sentient activity as a skilled activity, there can be an exploration of how these skills develop in gendered ways amongst both adults and young people. One aspect of mothers' caring that neither of the conceptualisations of caring appear to incorporate is that of 'training for independence', which was identified by Ribbens (1994). A new concept of 'developmental activity' was suggested, and its value will be assessed in this research.

The chapter then outlined research which indicates that both mothers and fathers may have gendered expectations and perceptions in relation to the illness behaviour and the care needed by their children. However, little research has been carried out in this area, and there is a particular lack of work exploring these gendered expectations from the perspective of both parents and young people. The proposed research aims to help fill this gap by exploring the ways in which the gendered views of mothers and young people intersect, and the consequences of this.

A key focus of the proposed research will be to explore the impact that care-giving has on the mothers of young people with a chronic illness, focusing on three specific areas. Firstly, the effects of the felt burden of responsibility and the ideology of competence (Anderson and Elfert 1989) will be explored. Secondly, the possible effects of the responsibility/autonomy conflict (Silverman 1987c) will be examined. In particular, the accusations of 'nagging' and 'mollycoddling' which can arise will be explored, as will the blaming of mothers for 'poor' control. Thirdly, the role that mothers may play as mediators for young people with a chronic illness in both public and private settings will be examined. This research aims to explore the ways in which this care-giving role may be affected by, and interact with, the gender of the young person.

4.5 The Research Questions

My review of the relevant literature leads to a clear formulation of the aims of this research which are:
1) To explore how gendered identities impact on both the meaning and the management of chronic illness, using diabetes and asthma as exemplars.

2) To explore the ways in which the gendered transition from 'dependent' childhood to 'independent' adulthood is related to autonomy in the management of chronic illness.

3) To examine how young people and parents, particularly mothers, negotiate changes in responsibilities in relation to the management of chronic illness, and to explore how this negotiation relates to gendered expectations of independence.

4) To explore the consequences that care-giving for teenagers with a chronic illness can have for mothers, particularly in terms of the difficult dilemma of encouraging young people to be autonomous in self-management, whilst still being held ultimately responsible for any problems which occur.
Chapter Five

RESEARCH DESIGN AND METHODOLOGICAL CONSIDERATIONS

The previous chapters have set out the background and the broad theoretical perspectives which informed the research. This chapter describes how the research was carried out, discussing some of the limitations which constrained it. Firstly the research design and choice of methodologies will be outlined. The chapter will then discuss the reality of the research process, paying particular attention to issues of access and to the conducting of the interviews.

5.1 Research Design

The aim of this study was to explore the ways in which the development of gendered identities might impact on how young people manage chronic illness. By examining how young people lived with chronic illness, I also hoped to be able to explore the ways in which young people and the parent most involved in care-giving ('key' parent) negotiated autonomy in terms of self-management. As previously discussed, there is often confusion between the terms independence and autonomy. Following Silverman (1987c), in this research independence and responsibility were seen as prerequisites of autonomy in the self-management of chronic illness.

The relatively narrow age range of 15-18 years was chosen, as this is commonly recognised as a transitional time when young people are moving towards independence, and I hoped this might highlight any gender differences in the negotiation of responsibility for the management of chronic illness. Qualitative methods seemed most appropriate as I wanted to explore these issues from the perspective of young people and their 'key' parent, and I hoped that in depth interviews would allow a detailed understanding of their perceptions (Fitzpatrick and Boulton 1994).

In order to better understand how young people and their parents negotiate responsibility for self-management, I decided to interview teenagers with two different chronic illnesses. By interviewing young people with different illnesses, I hoped to be able to explore the conceptual themes of gendered responsibility and independence more broadly. Asthma and diabetes were chosen as they are both 'lived-with' (Conrad 1987) illnesses which are not usually life-threatening on a daily basis. However, they both require high levels of self-
management, and they have similar high levels of personal responsibility for 'juggling' treatment (Bytheway and Furth 1996). I hoped that this would highlight differences in the development of gendered identities, and in the ways in which responsibility and independence are negotiated during adolescence. In addition, the gendered meanings of health and illness, and how these meanings relate to living with illness and to illness management, could be explored. Young people who had been diagnosed for at least one year were selected, in order to focus on issues of management as distinct from issues arising from the reaction to diagnosis.

One of the research questions was to explore how autonomy in self-management was negotiated between young people and parents, so it was essential to interview both the young person and the parent most involved in this negotiation separately. It was assumed that in most cases the parent interviewed would be the mother, as the vast majority of research indicates that mothers are more likely than fathers to be involved in the management of their child's illness.

A second key focus was exploring the development of gendered identities, so it was proposed that equal numbers of girls and boys would be interviewed. As young people with two different illnesses were to be studied, it was decided that ten girls and ten boys with asthma, and ten girls and ten boys with diabetes would be interviewed, as would their 'key' parent, making 40 pairs in total.

In addition to in depth interviews with young people and their parents, a secondary 'contextualising' research strategy was planned. This involved the collection of a range of qualitative data, including informal discussions with health professionals; conversations with people with experience of diabetes or asthma; documentary materials relating to diabetes, asthma and self-management; and observation in clinics, including hospital diabetes outpatient clinics and general practitioner (GP) asthma clinics. This would provide a wider understanding of the issues involved, and help inform my analysis.

The next part of this chapter discusses how the research was carried out. Firstly, the range of data collected for the secondary contextualising research strategy is described, followed by a longer section exploring issues relating to the interviews.
5.2 The Contextualising Research Strategy

5.2.1 Key Informants

Throughout the research period (May 1995-October 1996) I spoke to various people whom I felt would give me a particular insight into the ways in which teenagers live with diabetes or asthma. These included: two diabetes nurse specialists; two asthma nurse specialists; four practice nurses; one school nurse; two GPs; two diabetes consultants; one asthma consultant; and the 17 year old editor of 'Young Balance', a magazine for young people published by the British Diabetic Association. These conversations took the form of informal discussions, which I then wrote up in my field notes. During the period of my research I met a large number of people socially who had experience of young people with asthma or diabetes. Many insights were gained from these conversations, which were subsequently written up in my field notes.

5.2.2 Observation

During the research period I observed two hospital diabetes clinics, one hospital asthma clinic, and one GP asthma clinic. I also attended a self-help group linked to the British Diabetic Association for people with diabetes and their 'carers', and regularly attended study days (eight in total) about different aspects of living with diabetes or asthma. These were generally study days aimed at health professionals, where I was particularly interested in the discourse surrounding issues such as 'good' self-management. These observations helped highlight a number of issues which informed my research and analysis.

5.2.3 The Internet

I was alerted to the importance of the Internet to young people with diabetes by one of the mothers I interviewed, who told me that although her son declined to be interviewed he spent most of his days and evenings communicating on the Internet. Using the information which was relayed to me through his mother, I was able to connect with various user groups and bulletin boards, particularly those relating to diabetes. My impression was that these were used mainly by young men, and this proved a very helpful source of ideas for the research, particularly in terms of my analysis of the gendered meanings of chronic illness.
5.2.4 Documentary Evidence

I placed myself on the mailing lists of various organisations and regularly received literature and magazines from smaller self-help organisations, such as the Insulin Dependent Diabetes Trust, and from large groups such as the National Asthma Campaign and the British Diabetic Association, which produce literature for both health professionals and for people with diabetes or asthma. This data was very useful as it helped to highlight what some of the important issues were from the perspective of people with asthma and diabetes. During interviews people would often bring up a topic that they had read about in one of these magazines, and it helped to be aware of these issues.

5.3 Issues Relating to The Interviews

This section discusses the key issues which arose from the interviews which form the major part of this study. Firstly the ways in which access was negotiated with young people with diabetes and asthma will be discussed, and then specific issues which arose from conducting the interviews will be explored.

5.3.1 Negotiating Access to Young People with Diabetes

The vast majority of children and young people with diabetes are treated in paediatric or adult hospital based diabetes clinics. I planned to obtain most of my sample from four or five local hospitals in South West London, as I had previously worked in the area as a health visitor and had good contacts with some of the hospital staff. Hospitals were chosen which were situated in both inner-city and suburban areas in order to obtain a wide range of respondents. In order to explore more fully the ways in which responsibility for self-management was negotiated, I also felt it was important to interview young people with diabetes who did not attend medical appointments regularly, or who were perceived by health professionals as being 'non-compliant'.

In relation to access, I decided that consent for me to contact the young person and the parent should be obtained by the GP, practice nurse, hospital consultant or diabetes nurse specialist. I then planned to send a letter separately to both the young person and the parent explaining the purpose of the research. Separate letters to young people and their parents would be sent in an attempt to underline the fact that either person could refuse to be interviewed. This would be followed up with a telephone call to clarify any issues, and to arrange interviews where verbal consent was given. Written consent from both respondents would be obtained separately before the start of each interview.
The first hospital (Hospital 1) that I approached was the hospital where I had completed my nurse training, and where I still had personal contacts which facilitated access. I met the consultant during an outpatient clinic to explain the research. He agreed to refer young people and supported my Ethics Committee application, which meant that it was approved very speedily by chairman's action. Once approval was gained I was presented with a list of young people and their addresses. It was made clear that I should contact the respondents directly as there was no diabetes nurse specialist at this hospital, and the doctors were too busy to obtain initial consent for me. In my haste to get the research underway I decided to write to the parents and the young people separately explaining the project, stating that I would ring them in a few days to discuss the research. The letters also contained my phone number and address, and respondents were invited to contact me if they wished (Appendix A). The first mother I contacted was annoyed that her name and details had been given to me without her permission, and I then realised that my initial plan was correct, and that it would be preferable to use a health professional to negotiate access for me. However, this was not always possible and it highlights the problem of 'opt-in' versus 'opt-out' approaches to respondents (Alderson 1995), which will be discussed further in relation to the negotiation of access to young people with asthma.

In the next two hospitals (Hospitals 2 and 3) I made my initial approaches to the diabetes nurse specialists, as I knew that they would be of prime importance in gaining access to young people with diabetes. Having gained the informal approval of these 'gatekeepers', I contacted the consultants. This has been described by Dowell et al. (1995) as negotiating 'gatekeeper hierarchies' which they see as essential, stating: 'Access negotiated via the upper echelons of an institution will be worthless if it is foreclosed at the shop-floor level' (1995: 28).

Again, support was given and Ethics Committee approval was granted. I was then able to contact the nurse specialists who eventually gave me the details of young people they had spoken to, who had expressed an interest in participating. This could be a lengthy process, and it was difficult to judge how often it was appropriate to contact the nurses to ask whether they had any new names. Once I had received details of young people, I sent out separate letters (Appendix A) introducing myself and the project to both child and parents, stating that I would contact them by phone in a few days to discuss the research with them. Although there were benefits to this approach, including very few refusals out of the people approached, I did wonder if the young people perceived as more 'problematic' were being screened out by nurses. I think to a certain extent this was the case, and this will be discussed in the next section.
Table 5.1 (pg. 90) clarifies the sources of all of the young people interviewed with either diabetes or asthma. In total I submitted proposals to five Ethics Committees, as each hospital was under a different committee. I approached these hospitals in stages as my research proceeded, although this proved difficult to coordinate because of the workings of the various Ethics Committees. In relation to young people with diabetes, it can be seen that the sample also included one young person with diabetes who was cared for by her GP, with whom she had a very good relationship. She had previously attended a hospital clinic, and I was told about her by one of the hospital diabetes nurse specialists. In addition, four of the young people with diabetes were not obtained through hospitals or GP's, and they will now be discussed within the context of maximum variation sampling.

5.3.2 Maximum Variation Sampling

Many respondents were gained through a 'gatekeeper', usually a nurse, and there was always the risk that they were being selected in some way. I sometimes felt that 'compliant' young people had been picked for me, perhaps because the nurses found it easier to ring them and ask for initial consent, or because they were more likely to be seen in clinics. In order to explore the negotiation of responsibility for self-management more fully, I was also interested in interviewing young people who do not keep medical appointments. This has been described by Guba and Lincoln (1989) as maximum variation sampling, or a deliberate hunt for negative instances or variations. Despite making it clear that I would like to interview young people who were not regular clinic attenders, I did not appear to be gaining access to them, so I attempted to overcome this problem in various ways.

Firstly, I published a letter in 'Balance', a magazine for people with diabetes published by the British Diabetic Association, stating that I would be interested in hearing from anyone who would like to discuss the experience of being a teenager with diabetes. The replies that I received were not what I expected, but added a new dimension to the research. I received three replies from the mothers of young men who felt that their sons' diabetes was out of control (George, aged 17 years, Harry, aged 17 years, and Adrian, aged 21 years). I interviewed the mothers of Adrian and Harry, and because of geographical distance (the family live in Devon) I corresponded at length with George's mother. Unfortunately the boys themselves refused to be interviewed so they could not be included as pairs, but even so, they were very important in terms of the analysis, representing a group who would otherwise have been almost completely absent from the study.
TABLE 5.1

SOURCES OF YOUNG PEOPLE

<table>
<thead>
<tr>
<th>Source</th>
<th>Diabetes</th>
<th>Asthma</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital 1</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Hospital 2</td>
<td>2</td>
<td>3</td>
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<td>Hospital 3</td>
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<td></td>
<td>4</td>
</tr>
<tr>
<td>Hospital 4</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Hospital 5</td>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>GP 1</td>
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<td>GP 2</td>
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<td>GP 3</td>
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<td>GP 4</td>
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<td>GP 5</td>
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<td></td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>GP 7</td>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>'snowball'</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>'Balance'</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>20</strong></td>
<td><strong>20</strong></td>
<td><strong>40</strong></td>
</tr>
</tbody>
</table>

'Balance' Magazine:

- Interviewed the mothers of Adrian and Harry, and corresponded with George's mother.
- Interviewed two women in their early 20's - Emily and Louise.
I was also contacted by five young women in their early 20s who were keen to talk about their earlier experiences of living with diabetes. I interviewed the two from this group (Louise and Emily) who lived closest to me, and again, their experiences added a further dimension to the research findings. As they were outside my specified age-range they could not be included to make up my pairs of interviews with mothers and young people.

In addition, I was contacted by the mother of a 15 year old boy with diabetes from Essex. I subsequently interviewed both mother and son, and they appear in Table 5.1 under 'Balance', as one of my 20 pairs of young people with diabetes. This mother put me in contact with another 15 year old boy with diabetes whom I interviewed with his mother as another of my 20 pairs. This pair have been categorised in Table 5.1 as one of the 'snowball' pairs.

I used the 'snowball' technique of asking the young people I interviewed whether they knew of anyone else with diabetes who might consider being interviewed. I gained access to two young people and their mothers in this way who helped make up the 20 pairs of mothers and young people with diabetes.

5.3.3 Negotiating Access to Young People with Asthma

Most children and young people with asthma are treated by their GP, although those with more severe disease may attend a hospital outpatient clinic, so I planned to obtain my sample from both of these sources. Asthma is a much more variable condition than diabetes, and I did not want to interview young people with very mild asthma who only occasionally used bronchodilators. I therefore planned to recruit young people who were prescribed regular inhaled anti-inflammatory agents (preventers) in addition to bronchodilators (relievers).

Having previously worked for ten years as a health visitor in the area, I naively did not anticipate any problems in gaining access to young people with asthma via GPs. Initially I approached practices where I knew the practice nurse or doctor, or both. I also made contact with the local Asthma Advisory Group which consists of nurses, GPs, hospital consultants and public health consultants interested in asthma. They were extremely helpful, and agreed to help with the research by providing the names of young people to interview.

The first GPs I approached did not ask about Ethics Committee approval, but they felt that 'patients' permission should be gained before their details were given to me. One of the GPs asked me to contact the GP representative on the Local Medical Committee, which I did. I was told that there was no formal procedure for gaining access to the patients of GPs,
but I was advised that preferably GPs should make the initial approach to patients. The GP representative also felt that for my protection I should treat all young people under 18 years of age as 'minors', and parental permission should be gained on their behalf. As this would go against my whole research approach I contacted the Royal College of General Practitioners, and although they did not have any formal protocol, they felt that young people could give their own consent to participate in interviews. Other GPs I approached were happy for me to make the initial contact on the understanding that I had Ethics Committee approval, even though this had been obtained in relation to contacting young people through hospitals.

One issue was who should make the initial approach to young people, and how the approach should be made. In most cases the practice nurse was allocated the task. In one practice I was asked to pay for the practice nurse's time taken in making arrangements. In another, the practice nurse identified 12 young people with asthma from the computerised asthma register, but when she finally contacted me she had only been able to contact two people because of her work load. It should be noted that in many cases I knew the practice nurses and the GPs from my previous role as health visitor, and although this helped with access, it did not solve all the difficulties. Having been on the 'other side' of research in my previous employment, I felt guilty asking these very busy nurses to take on yet another task on my behalf, and the difficulty was judging how far to push in terms of reminding them.

To a certain extent I was able to test the 'opt-in' approach (Alderson 1995). For example, in one general practice the GP stated that patients should be sent a letter asking them to contact the practice if they were interested in participating in the research. Unfortunately I did not obtain any respondents from that practice, although it is difficult to be clear about the reasons for this. I felt that I had 'lost control' of the process, as it was very difficult to keep ringing the practice manager to ask whether she had received any replies, and the receptionists did not know who I was or what I was talking about when I rang to enquire. In another practice, letters were sent out asking young people with asthma to contact me directly, either by phone or letter (a stamped addressed envelope was included) if they wanted to participate in the research. Again, I did not obtain any respondents from that practice. In hindsight, the vast majority of the people I contacted were very keen to be interviewed, but many said that they would not have bothered to contact me if I had not rung them.

A further problem with identifying young people through GPs was the unsuitability of some of the referrals, in that sometimes the asthma was so mild that respondents only used an inhaler once or twice a month. This was despite the fact that they were recorded as
receiving prescriptions for preventer inhalers. I tried to ascertain the severity of their condition on my initial phone call, but this proved quite difficult, and I sometimes felt that the questions were rather intrusive on a first contact. In addition, some young people or their parents had a tendency to underplay symptoms over the phone, and the full impact of their condition could only be ascertained by interviewing them.

In total I contacted nine general practices, with twelve young people and their mothers eventually being interviewed from six of these practices. This research was conducted during a time of great change in general practice due to the health reforms, and there was a great variation in the ease of identifying respondents, depending on whether practices were computerised or not. Two practices asked me to contact them again in six months time as they were undergoing computerisation or major rebuilding, and did not feel able to take on any extra work.

As might be expected, the respondents I gained through hospital clinics tended to have more severe asthma. I approached the three consultants on the local Asthma Advisory Group, which meant that I received referrals from the four hospitals which they covered. Seven young people with asthma were interviewed from these hospitals. Three of these hospitals were the same ones that the young people I interviewed with diabetes came from, with Ethics Committee approval being granted simultaneously for both groups. Access to one young person with asthma was obtained using the 'snowball' technique.

5.3.4 Arranging the Interviews

I had decided to interview 'key' parents and young people separately, preferably in their own home, in order to compare and contrast the data obtained. Initially, I decided that if possible I would not interview the parent and young person sequentially, to enable a period of reflection between the interviews to occur. However in practice, when I rang to arrange the interviews almost all of the respondents preferred me to do both interviews on the same occasion. Arrangements were almost always made with the mother, and if the young person answered the phone, I was promptly passed on to their mother. This was noted by Brannen et al. (1994) in terms of their research with families, and it seems that mothers act as the 'gatekeeper' to the family in this situation. In all cases but one the mother was nominated as the 'key' parent in terms of helping the young person manage diabetes or asthma. Only one mother wanted to be interviewed at the local hospital because she felt there would be "no peace" at home.
I carried out the interviews between May 1995 and October 1996. The timing of the interviews was often difficult to arrange. Many mothers worked at least part-time, and young people tended to be at school for most of the day, although the older ones often spent less time at school. Many interviews were arranged for the evenings, and I was aware of taking up precious time in what for mothers and young people was often a busy schedule. The young people usually had homework to do, and again I was conscious of time. Many were taking GCSEs or A levels, and I learned to arrange my interviews so that they did not clash with mock (January and February) or formal (May and June) exams. Interviews were almost always carried out in the sitting room, which sometimes meant that other members of the family were deprived of the use of the television. I was also aware of other family members being involved in extra work, such as trying to keep young children amused and out of the room.

The order in which the interviews would be conducted was another area about which negotiation took place. In Brannen et al.'s (1991) study of young people, I was aware that they had decided that the young person should be interviewed after other household members, to reinforce the issue of confidentiality. Generally I let respondents choose the order in which they wanted to be interviewed, so as to cause the minimum inconvenience. This was preferable from a practical viewpoint, as often one or other of the respondents had something else that they needed to do at a certain time. Young people were often keen not to be interviewed between 7.30pm and 8pm, which coincided with 'Eastenders' and 'Coronation Street', and I often had to juggle boys' interviews around 'Match of the Day' on a Sunday afternoon. In terms of the data, it did not appear to make a difference who was interviewed first. However, on one occasion I was asked by a mother to reveal details about what her son had said to me, and although she accepted my explanations of confidentiality and privacy, she appeared surprised that this related to her son as well as to herself.

5.3.5 Gaining Consent

The research was bound by the British Sociological Association's guidelines for professional conduct and ethical practice. However, I was aware that there might be specific issues with regard to conducting research with young people. I read around this area as much as possible, and found Priscilla Alderson's book, 'Children's Consent to Surgery' (1993) particularly useful.

Before each interview, following an explanation of the project and issues relating to consent, the young person and their mother were given written consent forms to sign separately (Appendix B). I found it difficult to judge the amount of detail to go into before
each interview. For many young people this seemed to be the first time that they had been asked for their written consent, and some appeared surprised to be asked for it. Others had a tendency to rush to sign the form whilst I was going through it with them, as though they did not want to hold me up, and their consent was a foregone conclusion. I was anxious that young people knew that they did have a choice in all aspects of taking part in the research. In my initial phone call and again before the start of each interview, I went over the issue of consent. At the end of each interview, once the tape-recorder had been turned off, I asked each respondent why they had agreed to be interviewed partly from interest, but also to check again that there had been no coercion.

Permission was given to tape all of the interviews except for the one I carried out with a father. In her research Ribbens (1989) also found fathers to be more aware of the possible desirability of being cautious about what they said in the interview situation. However, in my situation it may have been because the father's job involved contact with the media.

Early in my PhD I was fortunate to come across the publications of CERES (Consumers for Ethics in Research). One which I found particularly useful was: 'Spreading the Word on Research, or Patient Information: how can we get it better?' (Alderson 1994). Later in the research process I was greatly influenced by a Barnardo's publication entitled 'Listening To Children - Children, Ethics and Social Research' (Alderson 1995). This thought provoking publication covers many important areas in relation to research with children and young people, and would certainly impact on any research I might do in the future.

5.3.6 The Structure of the Interviews

I aimed to use unstructured interviews as I wanted the interviews to be flexible, allowing young people and parents to pursue topics that were important to them. I also wanted to understand the meanings that they attributed to notions such as self-management. My conceptualisation of 'meanings' is similar to that of Charles et al. (1998), who state:

Following Blumer (1986) we conceptualise meanings as 'social products' that are developed through a formative process of interpretation, and hold that individuals' definitions of a situation are important guides to their behaviour (1998: 75).

An in depth approach was taken as far as is possible in a one-off interview, bearing in mind Cornwell's (1984) distinction between public and private accounts. Lofland and Lofland summarise the unstructured interview as:
..a guided conversation whose goal is to elicit from the interviewee rich, detailed materials that can be used in qualitative analysis....the intensive interview seeks to discover the informant's experience of a particular topic or situation (1984: 12).

They see the interview technique in terms of 'guided conversations' which enable the respondent's own account and meanings to take priority over the researcher's agenda. However, I was aware that this approach required the person being interviewed to respond in a particular way, as Martin and Pluck remark in relation to interviewing young people:

Non-directive interviewing calls for a rare skill and sensitivity and even at its best depends heavily on the self-confidence and articulate spontaneity of the respondent (1977: 3).

I felt that not all young people might be confident and spontaneous in the interview situation, so I developed interview guides which I could use either to guide the conversation, or in a more structured way, if necessary. The initial ideas for my interview guides came from the literature I had read, but the guides were updated as new areas emerged from the interviews, and others were found not to be particularly pertinent. I did not always remember to, or have time to discuss everything, as I was keen to pursue topics of interest raised by the respondents themselves. I used separate interview guides for young people and parents, and these can be found in Appendices C and D. I am aware that the way these guides appear in the Appendix makes them seem very structured. However, I was usually able to use the guides in an unstructured way, and the guides themselves were constantly changing and evolving. Their format in the Appendix is to give some idea of the range of topics that were discussed during the interviews. In some parts of the interviews I asked young people and their parents similar questions, in order to be able to compare and contrast perceptions. Other parts concentrated on aspects pertinent only to that individual. The majority of interviews lasted about one hour, but they ranged from between 30 minutes to over two hours.

I treated the first three pairs of interviews as pilot interviews, and as no major modifications were required, the data collected in these pilot interviews was analysed together with that collected in the main study.

5.3.7 Gender, Generation and Interviewing

The shortest interviews I carried out were with four of the young men. The mothers of these young men had warned me that their sons were not very talkative, but this still led me to ponder on the suitability of my research methods, particularly in terms of young men.
However, although the interviews were short they were generally informative, and the style appeared to suit other young men. Personally I found these particular interviews hard work, and was aware of my reliance on my interview guide to keep the interview going. On looking at these transcripts later it was obvious that I had been forced into participating in these interviews in a more directive way - there were many more questions from me, and little extra information was volunteered by the young men. I experimented by using vignettes on a few occasions, but these did not appear to make a noticeable difference. I was particularly conscious of both my age and gender when interviewing these young men, and turned to feminist methodological literature in an attempt to clarify my feelings about my research approach.

Initially, my motives for doing this were related to my lack of confidence in undertaking qualitative interviews, and the need to reassure myself that I had sufficient interviewing skills. The shorter interviews with boys came quite near the beginning of my research, when I was new to the interview situation. I was aware that partly because of my recent background in health visiting, I felt more confident in certain situations, such as interviewing mothers or health professionals, as opposed to interviewing teenage boys. I was also aware that ten years of more directive health visiting interviews was not the best preparation for in depth qualitative interviews.

However, the methodological literature threw up more questions than it answered, and at the time I remember feeling frustrated by this. I think I was hoping to find some kind of a check-list that I could run my finger down. For example, Phoenix (1994) discusses the matching of interviewer and respondent in relation to race and gender. Although she cites various ways in which the intersections of the race/gender positions of interviewer and interviewees can impact on the interview, she states that:

..the complexity of this impact, however, makes it difficult to be clear whether the matching of interviewees with interviewers on particular characteristics will produce 'better' or 'richer' data than not matching (1994: 66).

The situation seems little changed since Wise commented:

However, with few exceptions.....we know very little indeed about the influence of same sex and cross sex partnerships in interviewing. My own view is that structural position, personal style and skill are all involved in the interview in complex and sometimes contradictory ways that affect, not only the quantity, but the quality of information gathered (1987: 69).
I was relieved to find that other women researchers (McKee and O'Brien 1983) had found men to be generally more reticent in talking about their families and feelings, and that they had also noted the fact that fathers' interviews tended to be shorter and less 'conversational' than those with mothers. After discussing the transcripts and the interviews with my supervisor, I decided to continue with the same methodology, but in a more reflexive way. This meant that I tried to locate myself within the process of knowledge production, acknowledging that: 'the subjectivity of the researcher herself is part of research production' (Stanley 1987: 27). Issues relating to reflexivity will be discussed later in this chapter.

I eventually realised that the brevity of the responses from these boys partly reflected the ways in which they lived with diabetes or asthma. As will be discussed in the following chapters, these conditions occupied a very small place in the lives of these teenage boys, and were not seen as part of their social identities. This is not to say that I was complacent about the interviews, and over the course of the research process I heard about many different methodologies which other researchers were using with boys. However, the majority of the teenage boys appeared to enjoy the interviews, often surprising their mothers in relation to the length of time that they spoke for.

In general, the girls seemed very confident and articulate in the unstructured interview situation, and I often had the impression that they were used to talking in this way with friends.

Only one father was seen by his daughter to have been more involved in her care than her mother over an extended period of time, and consequently Cathy's father was the only father interviewed. The fact that this was an unusual situation was highlighted for me by the nurse who passed the family's details on to me, as she assumed Cathy's father to be a lone parent, never having seen the mother. Cathy's father declined to have his interview taped, the reason given being that he had a high profile media job, although he was happy for me to take notes.

In relation to my interviews with mothers, I felt much more at ease in this situation, particularly at the beginning of the research. This was partly because of my previous job as a health visitor where the majority of my day-to-day contacts were with mothers. I felt that to a large extent it was also because I am the mother of a teenage girl, and as Ribbens states:

..motherhood as a topic is quite a classless one, in that you can talk to anyone about their children regardless of their social group - there may be limits to this of course... (1989: 588).
DeVault (1990) highlights the ways in which woman-to-woman listening can be based on a particular type of 'unspoken knowledge'. However, she also states that this is not always the result of woman-to-woman interaction, drawing attention to the misunderstandings that can occur when one woman 'fails to hear' another. In hindsight, I think this occurred in some of the interviews that I conducted, as it was only gradually that I became aware of the extent of the extra physical work that mothers had often put in over the years in relation to their child's chronic illness. Having reflected on this I think it may be partly because the work is perceived by mothers as what any mother would do (as some in fact commented to me) and therefore not worthy of discussion. As DeVault states:

Most members of a society learn to interpret their experiences in terms of dominant language and meanings; thus, women themselves (researchers included) often have trouble seeing and talking clearly about their experiences (1990: 100).

DeVault (1990) reiterates the importance of grounding the interview in accounts of everyday activity such as how mothers actually spend their time at home, instead of in previously developed concepts such as 'housework'. In fact, the physical work of mothers forms an important part of my thesis although it was absent from the initial aims of my research.

5.3.8 Effects of the Interview on the Respondent

When asked, people often said that they had enjoyed the experience of talking about issues that they had rarely if ever discussed before. However, the mother of one young man with severe asthma told me after I had turned off the tape recorder at the end of the interview that our conversation had highlighted her problems for her, and made her reflect on whether she was handling various situations with her son in the best way. We discussed this in what I hope she found a supportive way. For me this experience served to make me even more conscious of the work of researchers such as McCall and Simmons (1969) who believe that real or feared harm will always occur to someone in a qualitative study, advising researchers to ask simply: 'To whom shall harm be done to in this study, and in what magnitude?' (1969: 276). Alderson (1993) makes a distinction between risks and harm, stating that risks are usually assumed to be the physical risks of invasive clinical research. She notes how psychosocial research is often quickly approved by medical Ethics Committees as non-invasive (as mine was), although it can be: 'intrusive, mentally wounding, embarrassing and anxiety-raising' (1993: 139). Alderson also draws attention to the difficulties involved in avoiding harm, stating that:
..a probing question may wound or offer a welcome opening.....people may enjoy a conversation at the time but later be unhappy about how much they revealed, or they may not enjoy it at the time but remember it gratefully (1993: 139).

She believes the research conversation to be a balance between respect for privacy and anxiety on the one hand, with encouragement for people to reveal themselves on the other. I was aware that this balance might be harder to achieve with young people who might be more reluctant to tell me if they did not want to continue with the interview for any reason. This served to make me reflect on my own roles in the research process.

5.3.9 My Roles In The Interview Process

On initial contact with 'gatekeepers' such as nurses and doctors some already knew me as a health visitor, and if they did not, I would usually 'drop' the fact into the conversation, as I believed it might help with negotiation of access. Although I have no way of knowing I believe it did help, as other researchers have found (Moyser 1988). To a certain extent I was positioning myself as an 'insider' in terms of health professionals. In the letter of information that I sent out to potential interviewees I described myself as a 'nurse researcher', again because I felt that this might help in negotiating access, which appeared to be the case. In addition, interviewees had usually been told by the 'gatekeeper' that I was a nurse, and they often checked this fact with me. In describing myself in this way, I realised that this would impact on the data produced as part of the research process, but on balance I think that the benefits outweighed the drawbacks.

Initially during interviews I was sometimes perceived as an expert on either diabetes or asthma, and I had to make it very clear that I was not. I also reinforced the fact that I was not connected with the health professionals who treated respondents. More problematic for me were the times when those interviewed asked me for advice on potentially more serious issues. For example, two young women asked me if the severe depression and suicidal thoughts which they suffered from were normal, and one mother asked me about her daughter's anorexia. Oakley (1981) states that researchers should use their power productively by giving any information and knowledge they may have which might be useful for the researched, and on this issue Skeggs comments:

How could I refuse? To concoct some vague response (as the research textbooks suggest) would have been an insult to them....At first I worried about this and overestimated my power, but....the information given is weighed up by the researched against their history and cultural background (1994: 82).
In hindsight, I had not given enough thought to these issues before starting out on the research, particularly in terms of what I would do if young people confided serious or potentially harmful problems to me. To a certain extent I was still thinking as a health visitor where there was collegiate support and a prescribed course of action for most eventualities. I had not fully appreciated how different the situation could be when interviewing for a research project. As Robinson remarks:

Surprisingly few nurse/midwife researchers seem to have thought through in advance what they will do if they hear or observe anything which suggests patients are at risk (1996: 43).

Robinson also highlights the fact that failure to take action against poor medical care is in itself a moral choice, stating that: 'Those who take no action against conspiracy can unwittingly become part of it' (1996: 43). There were many instances during the course of the research when respondents described episodes of what they thought of as sub-optimal treatment, or more difficult situations where respondents seemed reasonably happy with what I perceived as sub-optimal treatment, and Robinson's (1996) article helped me clarify my responses to these situations. In these circumstances it often seemed appropriate to describe examples of good care I had seen in the course of the research, thus providing respondents with knowledge which they could either choose to use, or ignore. In relation to the young people with specific problems such as depression, we discussed the issue particularly in terms of who they could approach for help.

5.3.10 Reciprocity - Debates and Dilemmas

Feminist literature has helped to open up the discussion about what is actually happening in the research interview situation. There are many dilemmas and debates around what is a very complex social encounter, and in this section only a few of these issues can be touched on. I found a paper by Jane Ribbens (1989) entitled 'Interviewing - an "unnatural situation"?' particularly useful in helping me clarify my thoughts over many of these debates, and the paper will be heavily drawn on in this section.

The issue of reciprocity and relationships in the interview situation was notably highlighted by Oakley (1981), who described interviewing women as a 'contradiction in terms'. I was aware that in the interview situation I was trying to project the persona of the friendly, empathetic listener. Deyhle et al. (1992) describe this as a 'fake persona', and Miles and Huberman (1994) call it 'subtle dishonesty' on the part of the interviewer. Although Ribbens (1989) sees this projection as perhaps the opposite of true reciprocal
interaction, she also acknowledges that for the researcher to talk about herself completely openly in the interview could significantly shift what is said, in unpredictable ways. I also found, as did Ribbens (1989), that on some occasions when I volunteered an experience of mine it was virtually ignored, and the interviewee carried on regardless. Ultimately, Ribbens believes that the interviewer needs to assess how the interview is conducted on an individual basis:

For some people, talking about yourself may be seen as making demands of them, whereas for others talking about yourself may be seen as being open with them (1989: 584).

The situation also varied depending on whether I was interviewing mothers or young people, and this relates to issues of power operating within research involving young people. I was less likely to volunteer information about myself to young people, and young people were less likely than mothers to ask me questions, either in terms of requesting information or personal details. Although I did not quantify it, it appeared to me that girls were more likely than boys to ask me for advice. Much of this feminist literature is written in terms of women interviewing other women, but I became very aware of the power I was automatically given - and perhaps unknowingly took - because of my age when I was interviewing young people. This was very pervasive, impacting on many parts of the interview process. Although I did my best to minimise these influences, I tend to agree with the conclusions of Ribbens:

Ultimately we have to take responsibility for the decisions we make, rather than trying to deny the power that we do have as researchers. While we may seek strategies to minimise this power, groups without power more generally in society are not in a position to assert power over the research process either, which is the essence of vulnerability (1989: 590).

Ribbens also questions the meaning of empathy in the interview situation, asking:

Does it mean the suspension of judgement and the endeavour to see things from the other person's view, or does it mean more than this, with an active emotional engagement with the interviewee? Are these two aspects inevitably entwined anyway? (1989: 586).

During the research process I also found myself thinking about how my 'empathy' might impact on the interview and 'data' collected. I was aware that part of the way I judged whether or not I had conducted a 'good' interview was the extent to which the respondent offered unprompted information, and to me a 'good' interview was often a long interview.
From a feminist perspective, Ribbens highlights one of the major problems of depth interviews, stating:

The particular paradox that is worrying about depth interviews is that you give the interviewee the power to control the interview itself, and yet as a result they put themselves very much in your hands by exposing themselves in a one-sided relationship. When you come to depart you take their words away, to be objectified as an interview transcript. In the end you are very powerful in this style of interviewing, and the absence of the questionnaire may obscure this all the more (1989: 587).

There are no easy answers to these issues, and ultimately, much depends on the willingness of the interviewer to be critical and reflexive about the research process.

Following the interviews I wrote to each young person and 'key' parent separately, thanking them for taking part in the research.

5.4 Data Analysis

Immediately following each pair of interviews I wrote brief notes as to how I felt the interviews went, highlighting any particular problems or things that had worked well. I listened to each tape as soon as possible after the interview, and wrote notes on key points raised. I transcribed sixteen of the early tapes myself verbatim, and although I found this a very frustrating, time-consuming experience, it was also beneficial in that it enabled me to get a feel for the data (Fielding 1993). The remainder of the interviews were transcribed verbatim for me by a typist. I had already decided that I did not want to selectively transcribe the interviews in case I missed important data. In addition, this was my first experience of qualitative research, and in these circumstances Strauss and Corbin (1990) recommend full transcription of all materials where possible. When the tapes, transcripts and discs were returned, I went through each one at length correcting any errors, and found that this also served to help me become familiar with the data. Throughout the research process I relistened to the tapes at various times, which allowed me to relive the interviews, and sometimes served to highlight issues that I had missed previously. In terms of data storage, tapes had no identifying details written on them, and when not being used they were stored in a locked filing cabinet in my home. The typist I employed to transcribe my tapes lived well out of the area in which I had carried out my interviews, and identifying details were removed from transcripts.

At the start of the research I had intended to analyse the data using the grounded theory perspective (Strauss and Corbin 1990) which allows categories to 'emerge' from the data.
However, when I started the interviews I already had some concepts in my mind from the literature I had read, such as the issue of stigma. At least initially, I was using these as definitive concepts and attempting to order my data using them, rather than using them as sensitising concepts (Blumer 1969). I was also aware of both the benefits and the drawbacks of my professional experience, which Strauss and Corbin see as one of the sources of theoretical sensitivity, stating:

The more professional experience, the richer the knowledge base and insight available to draw upon in the research. On the other hand, this kind of experience can also block you from seeing things that have become routine or "obvious" (1990: 42).

Despite this, the analysis did evolve into a 'modified' grounded theory approach in which themes and concepts emerged from the data to inform the theoretical framework. Examples of emergent categories included gendered notions of independence, and the gendered work of mothers as mediators. I started my analysis following the first pair of interviews, using both sensitising concepts and emerging theoretical categories to shape the data collection. Initially I used a system of open coding, which in practical terms meant examining transcripts line-by-line to identify what I thought was being said. Strauss and Corbin describe open coding as: 'the process of breaking down, examining, comparing, conceptualizing, and categorizing data' (1990: 61). I was then able to compare the coded data for similarities and differences in the experiences of people interviewed. From these initial very descriptive codes, conceptual categories slowly began to emerge, which eventually became part of my larger theoretical framework.

Charmaz (1995) states that two analytic processes contribute to raising terms to concepts, these being constant comparison, which was first described by Glaser and Strauss (1967), and continued questioning. As codes and categories emerged, questions were asked in order to establish the properties and dimensions of the category, and its relations to other categories. Strauss (1987) calls this the 'coding paradigm', stating that it is central to coding procedures. Through constant comparison of codes with each other, I was able to refine their fit to the emerging conceptual categories (Green 1998). For example, I compared the accounts young people with diabetes gave on how they managed their insulin injections on a day-to-day basis. This alerted me to the ways in which gender affected the number of daily injections given, and more generally, to the impact of gender on the management of chronic illness. There was constant to-ing and fro-ing between tapes, transcripts, fieldnotes and literature throughout the period of the research.
In addition, Green states that: 'The key to developing rigorous and valid theory using the constant comparative method is the search for deviant cases' (1998:1065). By publishing a letter in 'Balance' magazine, I was able to gain access to the mothers of young men whose diabetes was poorly controlled. They contrasted with the young men I accessed as part of my main sample, who, almost without exception, had good control of their diabetes. The inclusion of the young men with poor control enabled me to develop the theoretical depth of my analysis.

Having decided that my research strategy would include at least 80 in depth interviews I made the decision to use a computer software programme to help with the mechanics of coding the data and retrieving coded segments. I chose to use the NUD*IST programme, as it appeared to combine a theory building ability with user friendliness. NUD*IST also helps keep a historical record of the ideas which occur during data analysis, and this proved helpful when I needed to retrace the analytic steps I had taken when coding data. Without going into the details of this programme, I did find it very useful in helping me to order and sort data into codes and concepts. I was aware of criticism that there might be an increased danger of taking data out of context (Richards and Richards 1994), but I did not find this a problem as I frequently referred back to the original transcripts and tapes. Using the programme allowed me to experiment with building theories, and it also helped me to be more confident that I had complete retrieval of all the relevant coded material under particular headings. This in turn helped me to check whether what I thought were 'common themes' in interviews really were 'common', and to a certain extent this operated as a validation check.

The qualitative data gathered in relation to the secondary 'contextualising' research strategy also informed the analysis of the data. For example, the ways in which I found young men used the Internet helped sensitise me to the possible gendered meanings of chronic illness in terms of personal and social identities. The discourse surrounding self-management which occurred in my conversations with health professionals, and in the diabetes and asthma publications I read also helped me to explore the moral meanings attached to self-management.

Charmaz (1995) identifies a crucial part of the analytical process as writing and rewriting drafts for publication. For me, writing for my supervisor, for conference papers, and finally, writing and rewriting draft chapters for my thesis have proved invaluable in helping me sharpen my concepts and develop my theoretical framework. One of the benefits of doing a PhD has been the extended time period over which I have been able to carry out my data collection and analysis, and this has enabled me to develop and refine the research.
5.4.1 Validation

I carried out my interviews between May 1995 and October 1996, and this extended time period allowed me to test out and validate emerging theories with respondents. I had decided not to attempt validation with the original respondents because I had read of problems occurring when theories are developed which fall outside respondents' own explanatory systems (Dowell et al. 1995). For example, Burgess (1985) encountered considerable anger when she presented her analysis to her respondents, and I was unclear what I would do if respondents did disagree with what I wrote. Ribbens discusses this in terms of the limits of collaboration, stating:

I increasingly come to believe that this is the greatest power sociologists may have - to define other people's realities for them and others....Perhaps we have to take responsibility for ourselves, recognising that in the end we are not data collecting instruments for anyone, but are data creating social beings, and acknowledge our own presence within the accounts we give of other people's lives (1989: 589).

In addition, others such as Fielding and Fielding have argued that feedback from respondents should not be taken as direct validation of the researcher's analysis, but should be treated instead as 'yet another source of data and insight' (1986: 43).

Throughout the research process I had regular formal contact with my supervisor every four to six weeks. It is recognised that during the process of undertaking qualitative research the researcher becomes closely involved with the respondents and with the 'data' produced. Dowell et al. (1995) believe that in order to reflect on the data, researchers must have time to discuss their work and the themes emerging from it. They state that when this is done with an experienced colleague: 'there is also an opportunity for the validity of these themes to be challenged before they become entrenched beliefs' (1995: 37). Supervision offered me this opportunity.

5.5 Conclusions

This chapter has discussed the methodological framework of the study. Due to the exploratory nature of the study, I decided where possible to use unstructured in depth interviews with young people and parents, as the primary method of data collection. These were supported by a secondary 'contextualising' research strategy consisting of diverse qualitative data such as interviews with key informants and observation. With the benefit of hindsight it is always possible to think of ways in which one could improve the research
carried out. However, despite the limitations highlighted in this chapter, the interviews and other qualitative data proved successful for the purpose of this study.

The following chapters consider the results of the study in relation to both young people and their 'key' parent, who was in all cases but one, the mother. Where appropriate I have quoted from the transcripts of the recorded interviews, the quotes being selected as 'typical' of the particular perspective being discussed. Each quotation begins with either the pseudonym of the young person, or in the case of a young person's mother, the pseudonym of the young person is preceded by a capital M (e.g. Mtracey). In the one case where a father was interviewed, his quotes are prefixed with a capital F, followed by his daughter's name. My quotes are preceded by 'Int', short for interviewer. In accordance with transcript conventions, the symbols [ ] indicate words inserted by the author, and the symbols ..... indicate words omitted from the transcript by the author.

Terms
One of the practical implications arising from the work discussed in Chapter Two on the social constructions of adolescence and transition, is how best to refer to young people aged 15-18 years. As Alderson (1993) states, the term 'children' can be belittling, and in some texts, 'children' is replaced by 'young people', or 'young men and women'. However, these can also sound belittling, with their emphasis on age. When I asked young people which term they themselves preferred, the majority chose 'teenagers', 'teenage girls and boys', and 'girls and boys' in preference to 'young women and young men'. In the following chapters, therefore, all of these terms will be used interchangeably.
Chapter Six

MOTHERS AND TRANSITIONS TO GENDERED INDEPENDENCE

This is the first of two linked chapters which aim to explore the caring that mothers perform in relation to young people with a chronic illness, and the effects that this can have on mothers. The age range of 15-18 years is a time when young people are generally expected to negotiate independence, but in terms of a chronic illness, they are also expected to become autonomous in self-management. In this research, following Silverman (1987c), independence and responsibility are seen as prerequisites of autonomy. When young people have a chronic illness, mothers can be placed in a very difficult position. On the one hand, they are expected to encourage autonomy in self-management, whilst on the other hand, they are still held responsible if problems relating to their child's chronic illness occur. This issue will be explored in more detail in the following chapter, although it lies at the heart of much of what will be discussed in this chapter.

This chapter starts by examining briefly the roles that fathers play, and the ways in which these roles impact on mothers. It then explores the extent to which mothers have gendered views about young people's dependencies, and whether these views relate to the perceived health status of young people. The effects that managing gendered dependencies can have on mothers' care-giving is examined. Mason's (1996) conceptualisations of sentient activity and active sensibility will be used as sensitising concepts, to assess the extent to which they help describe and uncover the often invisible work that mothers - and sometimes fathers - do, in terms of managing a child's chronic illness. The proposed concept of 'developmental activity' will also be assessed in this chapter, whilst physical caring activity will be discussed in more detail in Chapter Seven.

6.1 The Role of Fathers

This research set out to examine the ways in which self-management is negotiated between young people with a chronic illness, and the parent they felt was most involved in their day-to-day care, whoever that might be. It soon became apparent that in nearly every case the mother was the parent most involved in care, and this was agreed by both mother and child when they were interviewed separately. However, this included three families headed by a lone mother. This is not to say that some fathers did not play an important role, and aspects of their work will now be described, partly to provide a justification for the rest of the chapter which will concentrate mainly on the role of mothers. Cathy's father was the only
father identified as the parent most involved in care, and therefore to be interviewed. It is acknowledged that relying on proxy reports of care by fathers is not the same as interviewing them in person.

The roles that fathers were reported to play varied a great deal, but the majority of fathers did not play a major part in the care of their child, with different reasons being given for their lack of involvement with care. Sometimes it was acknowledged that fathers' jobs meant that they were just not at home enough to provide care and support:

Msanjiv: I think it's mostly fallen to me until the last four years, because he [husband] used to travel around a lot. Now he doesn't travel a lot, he's around more, and so until the last four years I had to do everything, you know. He never used to go with us to the doctor's unless there is a special problem and the doctor wants to see him, but I mean, that hasn't bothered me because I took that on. I'm at home, I have more time than him, and that makes things much easier for both of us, if one person is in control and capable, and I do everything, sort of thing.

However, in most cases it was just accepted by mothers and young people that caring for health, but particularly illness, was the responsibility of mothers, and this had always been the situation. Because of this, mothers had developed expertise in dealing with illness, thus reinforcing their role as 'key' carer:

Int: How about your Dad, is he involved?
Julian: Not really.

Mjulian: I mean, if I go hypo [Mjulian is also diabetic] his father doesn't know what to do, so he wouldn't know what to do with Julian either.

Int: If you were ever worried about anything to do with your diabetes, who would you ask, would you ask your Mum or your Dad?
Martin: Yes, my Mum.
Int: So she would be the main person, even though your Dad's got diabetes?
Martin: Yes.

Mtracey: He worries, he does worry about it especially if she's late in. He can tell by looking at her as well, at a glance, but he won't say to her, he won't say, "oh, your blood sugar's low", he'll say, "look at the state of her face, her blood's low", and he'll tell me. So I say, "why won't you say, you tell her", but he says, "get her sorted out". He probably doesn't want the row.

In some families, fathers were not seen to be very 'good' at dealing with illness:
Carol: Well, if I get an asthma attack he really panics, he does - very panicky, and when I had my operation he got really upset....I'm not as close to him [compared to her mother] but he's there if I need him, I know that.

Mcarol: He's not really been on his own with her and he's not very good when the children aren't well, not really - he's not very good at all really.

Susan: Dad doesn't like blood and he doesn't like the thought of needles and I think he basically blocked it out of his mind, and he didn't like the thought of me doing them [injections] either.

Msusan: John [husband] would say, "I've got to go to work, I've got an important meeting", so I was left with the decisions to make all the time, I was left. Once, he took time off work.

The quotes above help illustrate how caring can come to be socially constructed as the work of women, which supports the work of Ungerson (1983b) and others. I will now discuss families in which fathers performed caring activities.

Some fathers were seen to have been helpful, although this was not usually in relation to the day-to-day work that mothers were involved in. Here, Ben's mother refers to the extra washing that she had to undertake because of Ben's eczema, which is often linked with asthma:

Mben: He was very good, yes, because he's a paramedic, so, oh yes, I couldn't fault him in that way really. But because he was on nights and things like that, so you ultimately have more of the responsibility and definitely, yes, and the washing and other things, but he was very good.

Others were acknowledged to have played an important role, either emotionally or practically:

Katie: And I mean Dad's had various things wrong with him, and every so often I get really depressed about it [diabetes] and he'll say, "well, I know how you feel", and I can take that from him because I know that he does know, he's been through something similar.

Sharon: I think my Mum as well and my Dad, but more my friends as well....when I was younger I was a Daddy's girl, because when I was in hospital [for eczema] my Dad was always with me and I wouldn't let no-one else bandage me or cream me, it was always my Dad.
Msharon: No, he was great, he used to stay, he used to take his turn staying at the hospital too. My husband did more than me when Sharon had the eczema.

In some families, husbands played an important role by supporting wives emotionally:

Mjemma: We're lucky, Peter and I, we've got each other so, you know, we can talk about it, and, you know, we'll go down to the river and go to the pub and have a chat, and it's no problem.

Mmartin: I'm lucky with John. He is very supportive and always helps out and I think that's good, you know. We've always had a good relationship and the days that I'm, "oh, I can't", he's like, "oh, I'll do it".

Two fathers played an important role mediating between mothers and daughters:

Malice: Actually, in a way I'm quite glad that my husband's been much more on her side and with my sort of - like, this attitude, I think Andrew's been very good for me on that because I probably would have got hysterical about it and, you know, "we're not doing it right", you know.

Becky: Sometimes my Dad just sort of brings her back down to earth, and says, you know, "you've got to stop doing this, she is the child, you've got to be strong for her, you've got to stop worrying so much, because if she's confident, then you've got to trust in her own confidence".....whereas my Dad would say, "look Becky, you've got to understand she's your mother, she's got to, that's her job to worry, she is going to worry". and then he'd say to my Mum, "you know, she is the child, if she's confident about it or even if she's not but she's still going to do it anyway, you've got to accept that".

In their research on the unequal division of the domestic workload in 'dual earner' partnerships, Brannen and Moss (1991) also found that women accommodated the inequality by using a number of strategies, which included giving priority to the importance of the emotional support, rather than the limited practical support of their husbands. In this research, even in those families where fathers helped or shared some of the caring activities, the major 'role responsibility' (Oakley 1985) typically remained with the mother.

In only four of the 40 pairs that I interviewed did both parents appear to play a more equal role in caring. Sharon's father had done so when she was young. Alice's father was an actor which meant that he was at home during the day, and thus available to care, although Alice's mother also worked from home. Nigel's father played a more equal role in caring, although he worked full-time. In Cathy's family, her father was a freelance musician, which meant that he was often at home during the day, whilst his wife, who was
a teacher, was at home during the evening and at night. Here, Cathy talks about why she thinks her father is the main carer:

Cathy: It was more my Dad, he sort of - my Mum was too panicky and worrying and she didn't know too much about it [asthma]. Like, she's a teacher, so if I had an outpatients appointment it would be my Dad that came with me, so he sort of knew more about it than my Mum did, and she'd get worried.... my Dad was looking to learn about it and see how he could help, and it was sort of him that would tell the doctors what to do and say how I was feeling.

The quotes cited above, and Cathy's in particular, support the views of Segal (1987), Morgan (1996), and others who believe the caring role to be socially constructed as the work of women. In this research fathers were found to be capable of performing sensitive care, although only Cathy's father was seen as the main carer. As Oakley argues:

Men's potential to be active and involved fathers is not in question; what is in question is why so few of them assume this commitment... (1986: 90).

The caring role had been taken on by Cathy's father partly as a result of him having a job which meant that he, unlike his wife, was at home during the day to care for Cathy if she required it, and he was also free to accompany Cathy to hospital appointments. In this way he had developed the expertise that mothers are usually seen to have, although other fathers who were at home in the day did not perform this role. To a certain extent this supports the claims of Segal (1987) and others who believe that there has been a failure to examine alternative connections between women's 'special qualities' and women's subordination. In addition, the fact that the nurse who gave me the details of Cathy and her father assumed him to be a lone parent illustrates the gendered expectations which operate in terms of mothers and fathers. In this research, it seems that where women and men lived together in a more egalitarian relationship, and fathers' jobs meant that they were at home more during the day, particularly if they were the only parent at home, the similarities between women and men in terms of caring became more apparent.

Mason's (1996) concept of active sensibility is useful here because it encourages the exploration of specific relationships within social and cultural contexts, and Mason argues that caring processes cannot underpin the construction of gender differences, or gendered moralities. As Mason (1996) claims, this allows a more sensitive analysis of the ways in which gender, caring and family relations intersect relationally to produce differences between women, between men and women, and also between men. Using the concept of
active sensibility thus allows the variety of caring situations found in this research to be explored.

In the vast majority of families most of the responsibility for care fell on mothers, and this appeared to be accepted unquestioningly by mothers and young people. The majority of mothers appeared to accept that their child's health was their 24 hour a day responsibility, and few seriously questioned their husband's/partner's minimal role in relation to health care. This supports the work of Ungerson (1983b) and Wilkin (1979), who found that mothers both dictated and upheld the motherhood model, thus reinforcing the exclusion of men from caring. However, it must also be recognised that not 'displaying competence' in the care of children can have serious consequences for mothers, and this will be discussed in more detail in the following chapter.

The role of fathers also impacted on mothers' paid employment prospects, which served to 'lock' them further into the main caring role, and this will now be discussed.

6.2 The Paid Employment of Mothers

The paid employment prospects of mothers could be severely affected by their child's chronic illness. Middle-class mothers tended to have more flexibility, either through their jobs which were often professional and tended to offer greater flexibility of working hours, or because a higher household income gave them the option of not working. Working flexibly could still affect their employment prospects, although this was rarely commented on by mothers. Working-class mothers either did not have paid employment, or tended to have jobs which offered less flexibility. It is hard to make any generalisations about whether the employment of mothers was affected by the gender of their child as Hill and Zimmerman (1995) found, because so many other factors impacted on the decisions mothers made in relation to seeking paid employment:

Martin: I obviously took the job at his school because, you know, you go down and you do the finger pricks, the lunch time injection and things like that, so that was definitely a reason that I took that job and I just started off down there as a dinner lady.

Msusan: My boss would say, "for goodness sake, go home and collect her". Now, had it not been over the road there was no question I would ever have been able to keep working...I was usually the one, I'd just stay off work. I'd get work, bring some work home or whatever (college administrator).

Mark: It would have been very difficult, I mean, I haven't been able to get a job because of this reason, because I knew as soon as I'd be in
employment they wouldn't want me because they'd [school] keep ringing me up, and I couldn't expect my parents to look after him every day (lone parent).

Mbecky: I mean, I'm lucky in one respect in that my work is quite flexible, I mean, I just stopped work when she was diagnosed so I could give it my full attention. I was off work for about 15 months, well, 13 months before I actually got some work after Becky was diagnosed diabetic, and I wouldn't, there was no way I could have worked when she was initially diagnosed, I couldn't possibly (journalist).

Mkatie: I was always predominantly a full-time mum and any work that I did was part-time and was always able to be dropped if anybody was ill. that's always been the arrangement.

Manthony: I don't work full-time because if something did go wrong I don't want to sort of put it onto somebody else having to do my job for me if you like. It suits me not to have the responsibility, to be able to say, "no, I can't come in today" (part-time supply teacher).

Mothers who were not in paid employment also made themselves 'available' for their children:

Msimon: I don't work, I'm always here when he comes home from school every day, at the weekends. I'm not out all the time at the weekends, you know, it might just be for a few hours, it could be just at lunchtime 'til teatime, or whatever so - I'm always here, I don't really go out much at night or anything.

Mcarol: Yes, when the weather's hot or, you know, I do get a bit worried if I go too far away.

This section supports the work of both James (1992), who highlighted the 24 hour, 'on-call' responsibility which generally falls on women, and the work of Brannen et al. (1994), who found that most mothers felt that they had fitted their employment around their families. It appears that the 'on-call' responsibility can affect the employment prospects of mothers, and as mothers are then available to care this serves both to 'lock' them further into these caring responsibilities, and to 'lock' fathers out. Combined with the previous section, this supports those such as Segal (1987) who argue that there are powerful economic, structural, cultural and ideological forces which ensure that women predominate as carers.
6.3 Mothers' Views of Gendered Dependencies

As the mothers in this research were found to play the major role in both childrearing and managing illness within the family, it is their views and experiences which are focused on for the remainder of the chapter. As previously discussed, there has been little research on the effects of the child's gender on mothers' care-giving, particularly in relation to chronic illness. Hill and Zimmerman (1995) found that the mothers of sons with sickle-cell disease were more likely to perceive their child as sicker, and to invest more effort in their care-giving than did the mothers of daughters, who described their child as more willing to undertake self-care. One of the aims of this study was to explore what findings emerged from a sample of young people with different chronic illnesses. Firstly, this section will examine whether mothers have gendered views of the self-management abilities of young people, and secondly, it will look at whether these views relate to perceived gender differences in health status that mothers may have in relation to their daughters and sons.

6.3.1 Perceived Self-Management Abilities

In the analysis of interviews with mothers, the mothers of girls were much more likely to talk in terms of their daughters being independent and responsible, both in general and in relation to disease management:

Msharon: I look at her now, I look at my son who's 10 and he could never do what Sharon's done, definitely not. Sharon grew up very quick, you know, she is a very mature young lady even now.

Mjane: But it's the same kind of thing, you know, them taking their own medication, whereas Jane's quite self sufficient, she's quite independent, I don't know whether it's a thing with girls rather than boys, I don't know, but I find that she's more independent, far more so than George (son).

Mmartin: Girls always seem more organised I find, and you know, she'll take the little blood testing kit or whatever for going away, everything is packed and organised whereas Martin will, as we're driving down the road, "oh, did you get my insulin?" (son aged 15 years and daughter aged 12 years with diabetes).

Mclare: Well, looking at the two of them, I know they are two different problems and he was much younger, but I think boys tend to just accept that you'll do things for them perhaps more than girls when they're younger, and you know, not question it so much either (son with asthma, daughter with diabetes).
Mben: I wasn't sure he'd taken them [inhalers] and I couldn't leave it to him, you know, and being boys, I think boys are sometimes younger aren't they?...I think boys are lazy about it.....Emma's far more mature, far more mature probably than he is now (son aged 18 years, daughter aged 13 years).

Mkevin: I think mums do tend to mollycoddle the boys more than the girls .....Yes, I suppose, because I mean it's more of an easier life, you know - Mum does it all I suppose, it's less for them......but Stacey, she's 16 and she's far more mature and takes a lot more responsibilities than what Kevin does - he's very laid back (son aged 18 years).

These findings concur with those of Hill and Zimmerman (1995), in that the mothers of boys interviewed for this study also felt that sons needed more support, and they therefore invested more effort in their care. However, this seemed to relate to a gendering notion of social age (Ginn and Arber 1995). Mothers perceived sons as being 'less mature' and 'lazy' in contrast to daughters, who were seen as independent and responsible, and capable of self-management.

6.3.2 Relationship Between Gendered Dependency and Health Status

This section will examine whether these gendered notions of dependency related to the perceived health status mothers had for their daughters and sons, as was found by Hill and Zimmerman (1995). Table 6.1 shows how mothers perceived the health of their child.

TABLE 6.1

<table>
<thead>
<tr>
<th>Perceived Health</th>
<th>Girls</th>
<th>Boys</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>very healthy</td>
<td>0</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>fairly healthy</td>
<td>12</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td>fairly unhealthy</td>
<td>7</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>very unhealthy</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Total 20 20 + 3 40 + 3

* mothers of George, Harry and Adrian
The mothers of boys were much more likely to describe their sons as very healthy, and this usually related to the amount of sport they played. Mothers of daughters often described their daughters as fairly healthy, sometimes more so than their daughters' own descriptions of themselves, but weight was often seen as an issue, particularly in relation to girls with diabetes. No mothers of girls described their daughters as very healthy. However, mothers were also less likely to describe their daughters as extremely unhealthy, as did the mothers of the few boys who were not seen to be in control of their illness. In terms of health, mothers seemed to judge girls by different criteria, such as the fact that they were rarely ill. or did not take much time off school. Boys were judged more on their ability to play sport, and on their general fitness levels.

One of the possible reasons that the results of this study differ from those of Hill and Zimmerman (1995) could be that their study focused on girls and boys with sickle cell disease, a disease in which the contact sports favoured by boys are not encouraged because complications may occur. In contrast, sport is encouraged and helps in the management of both asthma and diabetes. Whatever the reasons, in this study, unlike that of Hill and Zimmerman (1995), the mothers of boys did not seem to invest more effort in their care-giving for sons because they perceived them as sicker. Instead, boys were just perceived as in more need of care than girls, despite boys being seen as generally more healthy than girls. Conversely, the mothers of girls did not invest more effort in their care-giving for daughters, even though girls were generally perceived as less healthy than boys.

In this research care-giving appeared to relate more to mothers' gendered views of dependency than to their assessment of their child's health status. Daughters and sons were seen by mothers to have gendered identities in terms of their need for care. The majority of girls were seen by their mothers as being more responsible, mature and independent, particularly in terms of self-management. In contrast, many boys were seen as in need of help and support despite the fact that boys were generally seen as healthier than girls. The construction of social age appears to be gendered during mid to late adolescence, with girls generally seen as more mature, responsible and independent than boys of the same age, which supports the view of Ginn and Arber (1995).

6.4 Managing Gendered Dependencies

This chapter will now explore how these gendered views of dependency impacted on the care that mothers gave to young people.
As will be discussed in Chapter Eight, the boys interviewed were much more likely than the girls to describe diabetes or asthma as having minimal effects on their lives, and this relates to gendered ways of managing chronic illness. The majority of boys with diabetes managed their diabetes 'privately', almost completely from home, and this was often only possible because mothers put in a lot of supportive work at home. Mothers of boys appeared to subtly mute the effects of illness and dependency, by performing sentient activity (Mason 1996). For example, Julian is a 15 year old boy who developed diabetes when aged 13 years. He told me that his life had been affected by diabetes very little, but his mother performed a great deal of 'invisible' sentient activity to enable this to be the case:

Mjulian: If I'd insisted or the hospital had insisted that he does blood sugars at school and takes his insulin into school and all the rest of it, I think then, yes, there would have been a problem, but his diabetes is managed purely from here. Once he goes out of the door, as long as he's got some glucose tablets and his lunch in his bag, he's no different to anybody else, which is good really. Again, in some respects it's good, but in others you think, "Is he really aware of what he's got, is he really going to look after himself as he gets older?"

Here, Julian's mother recognises that she may be doing too good a job of making her work invisible.

In many cases, mothers seemed to 'absorb' emotions for boys, allowing their sons to exclude themselves from emotion work. Mothers recognised that it was difficult for boys to show their emotions, and although they sometimes encouraged boys to 'let go' in the privacy of their homes, this rarely happened:

Msimon: Do you know, he never even cried when he was told what he had wrong with him [diabetes], and I couldn't believe it. I was completely devastated, I was - just really couldn't believe it, like the rug had been pulled out from under me.....I must admit I didn't cry in front of him, but he knew, he knows I'm a worrier anyway and he knew I was so worried about him. I can remember he'd been home from hospital about a week, and the two of us were sitting together on the settee watching a film and I started talking to him, and I said, "well, you've amazed me the way you've coped, you haven't got upset or anything", because we were talking and I could see the tears were almost there, and he looked like he was going to, and I said, "if you feel like crying you cry, I'll never think any the less of you for it, don't ever think that". He said, "well, boys shouldn't cry", and I said, "that's rubbish, boys have got feelings or emotions like everybody else and so if you want to cry you cry, have a really good cry whenever you want, you've got every right to feel like wanting to cry". I said, "get it out of your system", and he didn't, he held it back, he said, "boys don't cry, I'll be alright".
This relates to the work of Mayall (1996), who highlights the fact that mothers of sons are faced with difficult and contradictory tasks in preparing their sons for a heavily enforced gendered social world, whilst making it clear that such stereotypes do not necessarily hold at home. However, it seems that by mid to late adolescence these stereotypes have had a profound influence on young people, and in Simon's case, he had absorbed the gendered view of expressing emotions dominant in his social world. As with the wives in Gordon's study (1995), this cast Simon's mother in the expressive role of providing emotional support for him, or doing his emotional work for him, which in turn, led to her becoming 'emotionally agitated'. In the same way, mothers of sons with asthma also talked about keeping their own emotions in check for the sake of their sons:

Mark: ...it's so difficult and I think to myself, you know, I should be a lot calmer for him really, because if I'm tense it's going to make him tense and therefore make it worse.

Terms such as 'emotional support' seem inadequate in describing the skilled nature of this activity, and Mason's (1996) concept of sentient activity appears more appropriate. Mason's (1996) conceptualisation also allows a focus on the potentially gruelling nature of sentient activity that can be heard through the quotes of both Simon's and Mark's mothers. Partly because of the ways in which mothers muted the gendered effects of illness and dependencies for their sons, the developmental activity required for daughters and sons differed, and this will now be discussed.

6.4.2 Gendered Developmental Activity

Ribbens' (1994) exploration of the work involved for mothers when encouraging independence in their children was discussed in Chapter Four. It was felt that a new concept to specifically describe this work might be helpful, and the term 'developmental activity' was proposed, as it appeared that Mason's (1996) concept of sentient activity might not adequately describe this specific aspect of care that mothers perform. Ribbens (1994) found this care differed depending on the meanings that independence had for mothers, but she did not explore the differential effects that the gender of the child might have.

In this study, the mothers of boys were more likely to describe having to actively encourage their sons to take on more responsibility for self-management as they got older. This was particularly the case with diabetes, which boys often managed from home with the help of their mothers. Table 6.2 shows the extent to which mothers were involved in their child's routine health care.
TABLE 6.2

The involvement of mothers in their child's routine health care

<table>
<thead>
<tr>
<th>Involvement Level</th>
<th>Girls</th>
<th>Boys</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>very involved</td>
<td>0</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3*</td>
<td>3*</td>
</tr>
<tr>
<td>involved in some aspects</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>not involved</td>
<td>15</td>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20</strong></td>
<td><strong>20 + 3</strong>*</td>
<td><strong>40 + 3</strong>*</td>
</tr>
</tbody>
</table>

* mothers of George, Harry and Adrian

As was the case for Ribbens (1994), independence was seen by mothers to include both physical self-care and decision-making skills. A future orientation was also seen as crucial, and this will be discussed in the following chapter. Mothers put much thought and planning into this developmental activity, trying to judge their son's 'readiness' for each step towards independence. The work was done in very subtle ways, and tended to be invisible, so it is perhaps not surprising that boys often appeared unaware of the work being done on their behalf. When discussing the care of their sons at an earlier age, mothers talked about letting them take their time in coming to terms with treatment:

**Mmartin:** I think, to ease them, if they're not ready don't push them, it will come in time. I used to think that when Martin first had to do his injection I used to say [to the clinic], "well, he won't do them", and they said, "don't worry, don't worry, it will come", and it did. It all took a long time but it just came eventually and I think that's quite a good way, not to force them and to make it a pressure, let them come around themselves (aged 15 years).

However as boys got older, situations had to be more actively managed. Mothers talked of planning ahead, of rehearsing for the future:

**Mkevin:** I'd take him there [to the doctor's] in the car and he'll actually say to me, "will you come in with me Mum?" and I actually said, "no I'm not". It's very hard because I stood there thinking, "well, have I done the right thing?", and I said, "no Kevin, you've got to do this on your own", and I felt quite cruel and that's only up until a few months ago (aged 18 years).
Mark: There have been times again when he's wanted me to be there and I've said, "no, you've got to start doing this on your own". It's been very difficult because I thought well, you know, if I keep on he's not going to be independent and in some ways he wants to be independent but in other ways he's not ready...this is what I am trying to do now, make him go step by step, because I find if I put too much on to him then he just rejects it and then it's stepping back rather than stepping forwards. And I will do the same eventually when he goes to the hospital, because at the moment I've been going in with him but I am thinking of next time, saying to him, "look, I'll wait in the Waiting Room while you go in", and do it that way, so at least he's got somebody to talk to but then he's independent on going in to the doctor's room (aged 18 years).

These quotes illustrate the subtle and invisible nature of much of this developmental activity, which usually went unrecognised. In fact, part of the skill and ultimate success of this activity lay in making it invisible, as Mark's mother illustrates. The same dilemmas Ribbens (1994) identified, such as how far to push children, and the paradox that training for independence is seen as another form of dependency need to be managed by mothers, were also seen in this research. However, a key difference is that in this study training for independence was found to relate very much to the gender of the young person. The closest that Mason's (1996) concept of sentient activity came to describing this particular area of care was in examples such as thinking through or planning relationships between oneself and others, but this does not appear to adequately describe this specific and very time consuming activity that mothers were found to be involved in.

As will be seen in Chapter Nine, almost without exception the girls interviewed for this study were more likely to have taken the initiative in terms of responsibility for self-management, often with little if any negotiation with mothers. However, this section will explore the problems this could bring for the mothers of girls. Whereas developmental activity was often under the control of the mothers of boys, the mothers of girls often had little if any control over the situation. As girls took their own steps towards autonomy in self-management, mothers were forced along at a pace which they considered was too fast for their daughters, leading to many anxieties. Developmental activity for the mothers of girls often consisted of mothers agreeing that girls could do what they wanted. For example, Becky's mother appears to be talking about general issues which would worry any parent, but the following quote relates very much to her specific worries about her daughter's diabetes:

Becky: I felt absolutely petrified every time that she'd have to take a new step without me, very difficult. I mean she's done things which I found really hard, like she wanted to go to an all night rave....I think I'd say the hardest thing has been just letting go, letting her do it and letting her decide what's best - not being in charge is quite hard because it's such a serious
matter. But I've not got to live with it, with my body, she is the one that has got to live with it so what we want is for her to, to be able to take charge. It's no use turning round when she's 21 or whatever and saying "right now, you know what to do". It takes so much, it's so gradual that you've got to let them do it in little ways till gradually they can do it in big ways..... She wants to go away on a package holiday with her friend and that will scare me, it certainly will, but I hope she does it because, I mean, you need to do things like that when you're young, otherwise they get to be real obstacles in your life and you daren't do them, because you just do a lot of these things when you're young, they just become acceptable, just nothing, whereas if you don't do them they are huge things (aged 17 years).

There was often conflict between daughters and mothers about what degree of independence was appropriate:

Msusan: I find that she's still difficult with this diabetes because what has now happened is that she refuses to let us know what goes on, refuses to let us know.... she takes too much on board herself and there's this, this, this you know, this independence bit. Sometimes I find she oversteps the mark by making decisions and doing things which I feel that she shouldn't be doing, and we think it's just not appropriate (aged 17 years).

There could also be conflict between mothers' views on independence and the views of, for example, health professionals:

Mjoanna: Like with the GP I can't go down there and say, "well look - I don't agree with what you're doing," you know....because she's 16 and as far as they're concerned she's an adult. I'm still her mother, and until she's 21 I should be consulted in some way....because I think that it's wrong that we don't know what's going on in their lives.

Mothers described how health professionals also had high expectations of girls' abilities to self-manage:

Msusan: I have never once given her an injection from the age of eight - she has always refused any help, and I used to think that maybe sometimes this was far, far too much for her. It was [from the medical profession], "it's your diabetes Susan, you're in control, you've got to handle this, and you'll be responsible", and I mean, she just sort of took this on board and that was the end of it.

The last quote illustrates some of the pressures on girls to become autonomous in self-management, but the focus here is on the difficulties that this can cause for mothers. For example, when girls became autonomous, it did not necessarily mean that they followed the prescribed medical regimes. Sometimes this was accepted as inevitable by mothers, and in
this situation developmental activity was seen in terms of allowing daughters to learn for the future. For example, Julia's mother talks about the unwillingness of her daughter to perform regular blood glucose tests:

Mjulia: But there isn't much you can do, you can't force a child, she will learn, and that's all you can do, wait and let her learn. I know it sounds, it sounds as if I don't care, but there isn't a way of forcing her to do what she doesn't want to do. Julia knows how important it is.

In addition, there was the problem for mothers of guessing the level of support that their daughters 'really' wanted:

Msusan: But you know, maybe she did need me, I don't know, it's difficult... But then that is me and maybe I'm not overtly sympathetic, I just don't know. I don't know whether maybe Susan resented that or not, but on the other hand she wanted - on the one hand maybe putting out this feeling of independence, maybe she was saying that, but didn't feel it, and maybe I was letting her down by not being more whatever it was she was needing - I don't know, it's terribly difficult. You just feel whatever you've done was wrong.

Despite these problems, mothers often consoled themselves with the positive point that their daughters were becoming autonomous in self-management:

Int: Do you find that difficult, not knowing what's going on?
Mjane: I'd like to know more, but there isn't a lot you can do, and at the same time I was quite pleased that she will take control of it [asthma] herself (aged 17 years).

In the very rare circumstances when girls did not take on the responsibility for self-management as expected, mothers could express resentment which was never expressed by the mothers of boys:

Malice: But I do, every night I know that I've got to remind her to have her insulin, in fact, I usually give it to her and I've stopped being resentful about that even (aged 16 years).
Int: So why were you resentful?
Malice: I just used to resent it a bit. I think a lot of it is something to do with growing up, you know. There are lots of things you have to do in this life ..., and this is just another layer, and I suspect that it's because it comes at a certain time when you think you've done all that and yet you've got all these other tasks thrust on to you and you've got to do them.
The type of help that Alice was seeking would generally be seen as acceptable for boys with diabetes, and mothers never expressed resentment about providing it. However, the same help given to girls may have a different meaning, perhaps because there is an expectation that girls will be autonomous in self-management.

As was discussed in Chapter Four, James (1992) claims that although the person cared for may be able to negotiate their requirements, responsibility for planning and co-ordinating remains with the carer. However, in relation to this study this appears to be a gendered issue, with the mothers of boys far more likely to be responsible for planning and co-ordinating care than the mothers of girls.

In terms of how independence may be evaluated within different frameworks of meaning as discussed by Ribbens (1994), it seemed that for the mothers of both girls and boys, independence for their child meant increased responsibility because of the need to be 'self-reliant in a hard world', particularly in terms of living with a chronic illness. However, these meanings were not merely imposed on young people by mothers, but were also actively constructed by the young people themselves, and it is the intersection of these meanings that leads to the gendered differences in developmental activity found amongst mothers.

In conclusion, this sub-section has shown that in this study, the mothers of sons were more involved in providing and supervising care, and consequently, were actively involved and in control of developmental activity. However, because of this responsibility, setting the 'right' pace for the activity could be a source of great worry for the mothers of boys. In contrast, because girls had often taken on their own self-management with little if any negotiation, the mothers of daughters were less likely to have any control of developmental activity. Although mothers were generally pleased about their daughters' autonomy in self-management, it also brought worries for mothers because of their lack of control over the situation. On the rare occasions when girls had not taken on responsibility for self-management as expected, mothers could express resentment which was never heard from the mothers of boys.

6.4.3 The Development of Gendered Roles and Dependencies

Mothers played a key role in the development of gendered roles and dependencies. In some cases, the mothers of sons expressed concern about who would take over the caring for their sons when they left home, and hope was expressed that this role could eventually be handed on to another woman. For example, when discussing Richard's future, his mother states:
Mrichard: He needs a stable life, and he'll need a good wife, who's going to look after him.

Similarly, Scott's mother says:

Mscott: I consider myself lucky that Scott is a bright, cheerful, positive person, and one day I'll pass him on to another woman who hopefully will be as devoted to him as I am.

Harry's mother states:

Mharry: And I think, how am I going to feel if he does meet somebody and they get married because she's then got to take it over. Like, I get his insulin for him, make sure that he's got it because he wouldn't, make sure he's got enough needles because he wouldn't do that either. If he gets married I've got to hand that over to somebody else and then I'm going to be thinking - I hope she's responsible.

These quotes illustrate the gendered notion of dependence. Mothers of daughters talked in a subtly different way, in that they expressed hopes that their daughters would marry someone who would look after them if they were ill, rather than someone to help them in everyday health maintenance. Mothers of sons could be seen to be 'smoothing the path' for boys, and hoping for a 'seamless' handing over of this task to another woman. Other mothers anticipated being involved in their sons' lives when they left home, although this was not something they shared with anyone else. This was often said in a joking way in which mothers tended to blame themselves for being 'overprotective':

Msimon: Yes, I do [worry about the future] because he's a bit of a - he's got his head in the clouds a little bit and he's always been a bit that way, a bit forgetful. His father's the same, they think the same, they are the same in so many ways and I think to myself, "well, what state will he be in when he's older?"...Obviously we had to tell the dentist he was diabetic, and the assistant said, "oh, my boyfriend is diabetic". She said to me, "do you know what, his mother phones him every morning from Glasgow to make sure he's taking his insulin, he's 27 years old". I laughed at the time, I said, "you're kidding", but when I came home and I said to my husband about it he said, "you're joking, fancy, at that age". I said, "yes", but I thought, "I could see me being like that, I could see me thinking - has he gone into a coma because he hasn't woken up?", you know. I know so long as he's under this roof I'll always be here and I'll always watch out for him.

In contrast to this, in terms of the development of gendered roles, mothers of girls (never boys) with asthma often had gendered expectations of them, such as that they should
help with housework. This included dusting their bedroom, or the house, even though
doing so might detrimentally affect their asthma:

Mleah: Her bedroom is quite dusty and it doesn't seem to affect her. I mean, I keep the rest of the house, but you can't keep it dust free around here....as I say, her bedroom needs a good dust but she won't do it, so that's up to her.

Leah: Sometimes dust affects me. If I'm - because I don't dust in my room, because if I do dust and it comes in my face and it makes me cough, then I leave it.

Mlisa: Dusting, that is one of Lisa's jobs, to dust once a week, does the polishing once a week, and she said, "well, my asthma", and I said, "well, you have to learn to live with it", you know.

The quotes relating to Leah and Lisa also support the research of Blaxter (1982), who found that the mothers of daughters were more likely than the mothers of sons to describe complaints of symptoms as 'moaning and groaning', 'acting up', or just 'playing on it'. This could also be supported by health professionals:

Cathy: I still have to clean and do the chores and I have to do my fair share, unfortunately. I did try and get Sara [asthma specialist nurse] to say that I couldn't but she told them, "oh no, get her dusting straight away", so for her to actually say that there is no doubt in their mind that I can't do it. But actually one time I had an asthma attack the day after I'd like, I'd got a pile of magazines and I thought I'd wipe them all down. After that my parents sort of thought, "oh, maybe it is that", you know, but I still have to do - I mean luckily the house isn't very dusty - still wash the floor and walls and stuff and get rid of the main dust.

This sub-section helps illustrate just a few of the ways in which gender is produced within families, and the importance of the role of mothers in this. The mothers of some of the boys were hoping to pass on their role in caring for their sons to other women, whereas in contrast, some of the girls were being prepared for their future role as carers within households, irrespective of any adverse consequences this might have for their asthma. This supports the work of Griffin (1986), amongst others, who highlight the ways in which family life helps construct gender identities.

6.4.4 Impact on Mothers of Child's Lack of Control Over Illness

In this study, young people's lack of control over their illness was usually linked with non-adherence to treatment. Of the 20 girls interviewed, 11 had intentionally had an often lengthy
and sometimes potentially harmful period of non-adherence to therapy, of which their mothers - and others - were usually unaware. In contrast, only two of the boys interviewed, Mark and Sanjiv, felt that they lacked control over their illness, although Mark told me that he kept strictly to his asthma treatment regime. The mothers of Harry, George and Adrian also reported that their sons were non-adherent to treatment, and had little control over their illness.

In this study, the mothers of teenage girls and boys who appeared to have given up hope of control over their illness were often affected quite differently. In the cases where boys had given up hope of gaining control, mothers' lives were always severely affected because of their knowledge of, and involvement in the situation:

Mark: He's had other illnesses as well, but since he's got rid of them the asthma somehow has taken over his life....and I feel so tense as well - I've got to the point where, oh, there's no point in making arrangements to go out anymore because I know what's going to happen, you know.

Mharry: He tells people that he'll be dead soon anyway so it doesn't matter what he does, and that seems to be his whole attitude really....so I've given up now, I might as well not say anything....he just doesn't want to do it [follow treatment regime], he doesn't want to know. As far as he's concerned, he hasn't got diabetes and he carries on as if he hasn't....Can't be bothered, that's all I get off of him, can't be bothered....I feel like I'm watching him kill himself, and there's nothing I can do about it, absolutely nothing - and, well, I just feel like tearing my hair out most of the time. I eat, sleep and drink worried, you know what I mean, because I'm just permanently worried about him all the time.

Madrian: I'm more concerned about how he'll ever live on his own more than anything else, because he's totally dependent on my providing all his food and money and everything for him. I mean, he couldn't support himself - I suppose one day he might be able to if this work that he's doing on the computer takes off - but otherwise I still look on him almost like a small child and being dependent on his Mum, you know, which is quite frightening sometimes when you think of the age that he is.

George's mother communicated with me by letter:

George: Within three months [of diagnosis] George had settled down into a routine of diet, exercise and injections, and was coping with bringing down his blood sugar - it didn't last long. At Christmas, George became upset that he couldn't indulge his sweet tooth as he used to. His blood sugar rose to levels never before seen. He refused to discuss his diabetes management with anyone, so I wrote to his consultant in desperation. By now he was saying things like, "If I go blind I'll just top myself".....He was failing at school and refusing to put any effort into GCSE revision - "What's the point?", was his favourite phrase. In October this year he had a violent
outburst at home, broke a window and stayed out all night...I would have been devastated but not surprised if he had attempted to take his life...The strain on the family (I have a husband who is away 3/5 of the time, and a 13 year old son) has been immense at times.

The mothers of Mark, Harry and Adrian are lone parents, and George's father is away a lot, and it may be that this factor also impacts on the ways in which the lives of these mothers are affected, in that they have total responsibility.

In contrast, mothers of girls were often unaware of the depression or despair that their daughters were feeling, because girls tended to hide these feelings from their family. This relates partly to gendered ways of managing chronic illness which will be discussed in more detail in Chapter Eight:

Mjane: Jane's quite self-sufficient, she's quite independent...she's sensible, she's got one [inhaler for asthma] in the car, one upstairs, she seems to be managing well....she has salbutamol and there is another one - I think she takes one once a day and one twice a day.

Jane: I'm supposed to take the brown one [preventer inhaler] twice a day, but I don't take it. I took it at first, then I stopped - when it was bad in the summer I took it for a while and then stopped again. I get asthma in the night, and have to get up, but I still don't take it. I take ventolin [reliever inhaler] every day, when I need it,...sometimes I can't be bothered - I get really depressed for no reason, and start crying. I feel like I don't want to live - it's stupid. I feel embarrassed saying it, I feel worthless.

This is not to say that mothers did not worry about daughters, but it somehow seems that the mothers of girls did not usually feel the overwhelming sole responsibility that the mothers of boys felt. This was partly because girls were seen to be autonomous and therefore responsible for self-management. In addition, the mothers of girls were not aware of problems, whereas the mothers of boys were totally involved in the situation. This supports and extends the research of Charmaz (1995), who found that some men used the uncertainty of chronic illness to keep hold of power and privilege in their homes. Wives who tried to cajole them in terms of treatment got responses such as: "'Why should I care what I eat? I'm going to die anyway" (1995: 273). This research suggests that some boys in middle to late adolescence also keep hold of power and privilege in relation to their mothers, in the same ways that middle aged men do with their wives.

This section has examined various ways in which mothers manage and help develop gendered dependencies. However, it is important to emphasise that it is not a question of mothers imposing their views on young people. Young people themselves also actively
construct these gendered dependencies, and it is the interaction of the two perspectives, plus the many outside influences of others such as health professionals, that results in these socially constructed gendered dependencies.

6.5 Conclusions

This chapter initially examined the role of fathers in relation to caring for young people. Fathers were found to be capable of performing sensitive care, which supports the view that the caring role is socially constructed as the work of women. However, in general, mothers took the major responsibility for care, frequently with little help from partners. This often severely affected their employment prospects, and as mothers were then available to care, this served to 'lock' mothers further into caring responsibilities, and to 'lock' fathers out.

The chapter explored the role of mothers in relation to gendered dependencies. These gendered dependencies did not relate to mothers' perceptions of the health of their child, appearing instead to be socially constructed and related to the gendering of social age (Ginn and Arber 1995). The mothers of boys with a chronic illness, particularly diabetes, were much more likely to be actively involved in caring for their sons, and in this way muted the effects of illness and gendered dependencies. However, this also led to a consequent increase in developmental activity which could be a source of anxiety for mothers. Mothers were so skilled at making their care for sons invisible, that boys themselves were often unaware of what was being done on their behalf. This activity sometimes became more obvious as boys got older and mothers felt under pressure to make them more autonomous in self-management. This led to many worries as mothers questioned whether they were putting too much pressure on their sons, although mothers did have some element of control over these situations.

In contrast, girls were much more likely to be seen as autonomous in terms of self-management, and consequently the mothers of daughters were less likely to be involved in disease management or developmental activity. This could cause conflict between mothers and daughters, because mothers often had little control over situations, which were usually controlled by girls and supported by health professionals. Due to their greater involvement, the mothers of boys who had given up hope of control of their illness were more often affected than the mothers of girls. To a certain extent, this indicates that boys of this age with a chronic illness keep hold of power and privilege in relation to their mothers, in the same way that men have been found to do with their wives (Charmaz 1995).
Mothers were found to play a part in the development of gendered roles and dependencies. The mothers of some of the boys in this study were hoping to pass on the day-to-day monitoring and caring role for their sons to another woman. In contrast, some of the girls were being prepared for their future role as carers within households, even when this had adverse effects on their chronic illness.

The meanings of independence and autonomy appear to be gendered. However, these meanings are not merely imposed on young people by mothers, but are also actively constructed by young people themselves. It is the interaction of these two perspectives plus the many outside influences that appears to result in socially constructed gendered dependencies.

Mason's (1996) concept of sentient activity was very useful in helping to describe and uncover the often invisible but very skilled work that the mothers in this study performed. This would otherwise have to be described as 'worrying', or subsumed under the concept of emotional labour. However, the concept of sentient activity did not adequately describe the developmental activity that mothers of young people, particularly young men, are involved in when smoothing their child's transition to autonomy in self-management. It appears that the concept of developmental activity may be a useful addition to that of sentient activity when describing this aspect of care by mothers.

Much of the previous work on caring, including that of James (1992), relates largely to women and caring. The concept of active sensibility allows a more sensitive analysis of the ways in which caring, gender and family relations intersect relationally to produce differences in caring. In addition, James' conceptualisation of caring allows the receiver of care to inhabit only a limited, passive role, whereas in this research both the young person and their mother were active in constructing roles. The concept of active sensibility recognises these more negotiated roles.
Chapter Seven

RESPONSIBILITY AND AUTONOMY - MOTHERS' CONFLICT?

This is the second of two linked chapters which explore the caring that mothers perform in relation to young people with a chronic illness, and the effects that this can have on mothers. This chapter will develop the work of Silverman (1987b) which was discussed earlier. Silverman drew attention to the difficult dilemma that parents of adolescents with a chronic illness can be placed in. They are expected to balance the conflicting norms of acting responsibly, with respecting the young person's autonomy and ability to self-manage. This chapter will focus on the particular pressures that mothers are placed under in terms of the potential autonomy/responsibility conflict. As discussed in the previous chapter, mothers are much more likely to be the parent with ultimate responsibility for caring for their child's health, and this chapter will explore the effects that operating within an 'ideology of competence' (Anderson and Elfert 1989) can have on mothers.

The work of Silverman (1987b) did not explore any effects that the young person's gender might have on mothers and this will be the second key focus of the chapter, although it is the interaction of these two issues which is important. Finally, this chapter will examine how mothers act as mediators and how they display competence in their caring, including the effect that the gender of their child can have on these areas.

7.1 Ultimate Responsibility

This section explores three specific ways in which mothers are blamed as a result of being held ultimately responsible for their child's health. This blame is related to the age of the young person, as the autonomy/responsibility conflict highlighted by Silverman (1987b) is a particular issue during adolescence. Silverman argues that parents are expected to respect their child's autonomy without being seen as 'permissive, 'uncaring', or 'irresponsible'. The first two reasons for mothers being blamed, blame for poor control and blame for 'mollycoddling' relate to the gender of the young person, and the third, blame for 'nagging' takes place in relation to both teenage girls and boys.
As was discussed in the previous chapter, the mothers of girls were far less likely to be involved in their child's care than the mothers of boys. However, when girls were autonomous in self-management but control was not seen as 'good', mothers were at risk of being blamed by health professionals and others, as they were still seen as ultimately responsible for their child's health. Mothers of daughters with diabetes in particular talked about episodes when they had been blamed for the poor control of their child's illness, and the following quotes illustrate the difficult position mothers can be placed in. For example, Tracey, Julia and Susan took responsibility for their diabetes, which is what health professionals had encouraged. Consequently, these mothers had played little part in the decisions their daughters made in relation to treatment, and often knew very little about them:

Mtracey: Her blood sugar's been out of control for a long time, whether or not she does everything by the book. They had her in hospital for two weeks monitoring her and giving her everything she should have, and her blood sugar's still up. They were saying, "she can't be taking it, you can't be doing it right", and I just said, "well, you take her in to hospital and you do it for her", and that's what they did and it was the same.

Mjulia: So I came in to see the top man [consultant], because I was furious. He said when Julia was in hospital I'm sneaking her in chocolates, and I said, "no, I'm not", and he said, "well, her sugars can't be still that high", and I said, "I'm not bringing her in food".

Msusan: And then with all this business with food they even had us in front of a counsellor. You were made to feel as if somehow or other all of the ups and downs [of blood glucose levels] were all to do with Susan manipulating us, or us as a family or whatever....you were really made to feel desperately guilty if these blood sugars weren't down.

The quotes also illustrate the ways in which psychological discourse has influenced health professionals understandings of situations, with the implication being that dysfunctional mothers and families are to blame for poor control. This supports the work of authors such as Askilden et al. (1993), who highlight the way in which the mother and mother-child relationship have been particularly focused on in relation to poor diabetes and asthma management.

Sometimes other people made the autonomy/responsibility conflict harder for mothers of girls, by questioning the amount of independence girls were 'allowed' by them, even though girls had often dictated the situation, and health professionals had encouraged it: 
Msusan: I mean, some people have said to me, you know, when she went on this diabetic camp, or on holiday, "how can you do that?", or whatever, and I said, "you don't think I'm not worrying do you?"

This section serves to illustrate the difficult position that mothers can be placed in. When girls became autonomous in self-management, mothers could still be blamed for the 'poor' control of their daughters' illness. Susan's mother was blamed for not caring enough, for not acting as a 'good' mother, even though Susan herself had chosen to go on the holidays, and health professionals had encouraged this as promoting autonomy in self-management. As discussed in Chapter Four, Anderson and Elfert (1989) draw attention to the 'ideology of competence' which they claim is internalised by women, and within this, the serious consequences that not 'displaying competence' has for mothers. They highlight the more complex issues involved when the child has a chronic illness, in that mothers often feel responsible for having 'created' a child with a health problem. These feelings of responsibility can put her competence into question, leading to overwhelming guilt and blame. It is not just that mothers are being accused of not 'displaying competence', it is the meaning that this has for mothers of young people, particularly those with a chronic illness. It also seems that it may be more difficult for mothers of young people with a chronic illness to display competence, because of the autonomy/responsibility conflict which occurs particularly in relation to this age-group.

7.1.2 Blame for Mollycoddling

On the other hand, mothers of sons were placed in an equally impossible position. They talked more in terms of being blamed for being over protective, for 'mollycoddling', and this again relates to the autonomy/responsibility conflict, and to the ultimate responsibility of mothers. 'Mollycoddling' is an interesting choice of word, and was used quite frequently. The Oxford Dictionary (Allen 1988) defines it as: 'to coddle, pamper; effeminate man or boy', and it is the latter definition that seems to lie at the heart of what mothers are being accused of by health professionals and other family members. This relates very much to the meanings of masculinities, and the threats that illness, particularly chronic illness, poses to masculinities:

Mharry: I used to [go to hospital appointments with her son], but then when he got to 17 they told me to stop going. They said, you know, "he's old enough to look after himself, he doesn't need you to come with him", but I feel that he does because I can tell them what he's doing and not doing whereas he won't, you see. He'll just say, "everything's fine, I'm fine", 133
and they believe him...I'm sure they think that of me, that I'm far too over protective with him, that I mollycoddle him, but I mean, they don't have to live with him and see him doing things that he shouldn't be doing, you know, and there is just nothing I can do and it just winds me up all the time, and I just feel, really I feel worn out with worry......that's what they've all said to me, "it's his diabetes, he's got it, it's his body, he's got to take care of himself, he knows when he feels ill or when he needs more insulin or less insulin", and I think, "but no - it's not just his because it affects us all". I mean, we're all in it together, because he's mine and I want to help him, you know, but it's like I'm not allowed to.

Mmark: That's what annoys me and this is how I've been treated all along, and I thought, "well, my mother's done it to me and nothing was said about that". We didn't find it abnormal for your parents or somebody to come to the hospital with you. I mean, even now, if I have an appointment myself she (mother) rings up and says, "would you like someone to come with you?", and sometimes I say "yes" and sometimes I say "no", and it's not because I can't cope, because I go and see the doctor on my own and she waits outside, and that's what I intend to do with Mark now.....and I thought, why do they shun it now, why do they say, "it's not right, it's abnormal".....and that puts pressure on a parent as well because you feel that. I think to myself, "well, am I mollycoddling him?", and then I think to myself, "well, if I am I've got to stop it"....It's been hard for me, maybe I have mollycoddled a bit, but I've had reason to. There have been times when I've thought, "I'm not, I've got to push him", and I've done that and it's backfired.

These quotes illustrate very clearly the gruelling effect that dealing with this conflict can have on mothers. Mothers were not only at risk of being blamed by health professionals, as other family members also accused them of mollycoddling:

Mkevin: I think mums do tend to mollycoddle the boys more than the girls....as Stacey [daughter] said, "you're to blame Mum", and looking back I think, "I suppose I am really", you know, because I should've let him take a bit more responsibility, but then again I think, when they've got asthma and I know what I was like myself as a child. If you worry or you get all panicky you can trigger attacks off, so I suppose you protect them from that, because obviously you don't want to trigger off attacks, you know.....But in the end, my husband said to me, "you've just got to let him do it and if he don't take them [inhalers] for a day or so that's entirely up to him". I knew what my husband was saying was right but it's very hard.....because although my husband's very good and that, because he's never actually had any illness himself, he's never experienced eczema, asthma, or any of them things, it's harder for him to understand. He put it down to the fact that I had mollycoddled him too much and, "let him grow up and he'll be fine". He was trying to sort of say, "well, toughen him up and it will go away". but that wasn't the answer, no.

MrRobert: And I think I also take all the stress as well, because I worry about it all the time and I think men tend to, to sort of think, "oh well. he's a boy, he can cope", but I think women tend to worry more. I tend to worry more about him I think than James [partner] does. I think he thinks I fuss a bit but
then I try not to be like that... I don't tend to talk about it a lot really, because I think men sort of see things differently to women. I think they just sort of think, "oh, he's a big lad, he's alright, stop worrying", but it isn't as easy as that.

The reported reaction of the fathers in the two quotes above supports the work of Duncombe and Marsden (1995), who found that men were likely to see women's emotional work with children as unnecessary and debilitating 'fussing'. However, in this research it was the fathers of sons who were far more likely to be reported as voicing this opinion. This is partly because girls were more likely to have taken control of self-management, so mothers were less likely to be involved in their care. Mollycoddling, or over protecting, appears to strike at the heart of the social construction of masculinities, threatening the successful transition of boys into 'proper men' (Prout 1986: 125). This is perhaps why it was such a source of anxiety for mothers, and why fathers became involved.

Mothers also discussed incidents when they received disapproval because they had not mollycoddled their sons as they were expected to by others:

Mrobert: I remember one day, it sounds quite cruel, he was at junior school, and I had a phone call about 10am to say Robert was feeling ill and could I come and get him. And when I got there he was crying his eyes out and it had been one of them awful mornings where he's playing up and he'd got angry and he hadn't done his homework and he didn't want to go to school - you know, one of them mornings, and he'd gone to school without his breakfast and when I went to pick him up, instead of being one of these really sympathetic mothers saying, "oh dear, what's wrong?", I said to him, "you know why you're like this don't you?", and this woman [school secretary] looked at me as if to say, "oh, you awful woman"...I said, "right, we're going home, I'll feed him and we'll be back within the hour", and this woman, I mean, you could see she was really sort of shocked.....Now other people would be, "oh, how wicked, how could you do that?", but to me that was the best philosophy for him because if I'd mollycoddled him and said, "ahhh", he could abuse that.

Mmark: I mean, I've had that experience with teachers. I sent him to school with a bad cold because he was always having time off and I said to him, "well, it's only a cold, you're going to school", and the teachers, he's come home and the teacher had really let rip - "how dare your mother bring you to school when you're like that?", and I thought, "well, I can't do anything right", you know, I found this all the way along.

These quotes illustrate the difficult, 'no win' situation that mothers of sons can be placed in when deciding on appropriate care. They run the risk of having their competence as mothers criticised which can be devastating for them. In addition, the quotes support the findings of Prout (1986) who noted that boys' claims to sickness were likely to be believed by teachers,
because of gendered notions that boys were more likely to be 'stoical' when ill. When attempting not to 'mollycoddle', mothers sometimes knowingly took risks, although never lightly. Mothers knew that ultimately they were responsible, and would be held responsible, for their child's health:

Mmark: Sometimes I've even made him go to college and I've dropped him off, and I can see he's not right and I've just driven off and left him at the station and I've thought, "oh, am I doing the right thing, what if it gets worse, I'll never live with myself", but I've done it and luckily enough it's never got worse, but - you know.

This sub-section illustrates the difficult situation that the mothers of boys with a chronic illness are placed in, in terms of the autonomy/responsibility conflict. As was seen in the previous chapter, teenage boys were less likely than teenage girls to be seen as autonomous in self-management, which meant that mothers were usually involved in care. Consequently, mothers also had to perform 'developmental activity' to encourage autonomy. One of the difficulties of developmental activity noted in Chapter Six was that of setting the right pace for the child. In this research it was found that the mothers of boys often ran the risk of being accused of mollycoddling if the pace was seen by others as too slow. This blame could come from health professionals, or other family members, particularly fathers. It was argued that fathers are particularly likely to become involved in this aspect of care because of the threat that mollycoddling poses for the successful transition of boys to 'proper' men. This supports and extends the work of Duncombe and Marsden (1995), who found that men were likely to see women's emotional work with children as unnecessary and debilitating 'fussing'. In this research, fathers' attitudes to fussing related strongly to the child's gender. However, mothers could be accused of not protecting their sons enough, and this also placed them in difficult situations.

There were no reported incidences of mollycoddling in relation to girls. This may be because girls were more likely to be autonomous in self-management, but it may also be that there is not so much blame attached to mollycoddling girls, because of the lesser threat it poses for the construction of femininities as opposed to masculinities.

7.1.3 Blame for 'Nagging'

Mothers of both daughters and sons, particularly those with diabetes, almost invariably said that they 'nagged', and tended to blame themselves for this. Young people also confirmed that it was mothers, not fathers, who 'nagged'. Silverman (1987b) highlights this issue in terms of teenagers with a chronic illness, arguing that parents are placed in very difficult
situation, expected to be responsible without 'nagging'. However, this research found that it was not usually parents who were placed in this difficult situation, but specifically, mothers:

Mjulian: Yes, he always thinks I'm nagging, always - "Mum, don't nag" - "I'm not nagging, I'm just discussing something" - "you're nagging". "Oh mum, don't keep on", and the usual.

Mtracey: So, yes, I do worry a lot and because I worry I nag her and because I nag her she shouts, and because she shouts I shout, and then we end up at it ......to her I'm always moaning, but to me I'm only moaning to make sure she's done it....she thinks I nag but then all mums do.

Mbecky: I used to be terrible and I still am to a certain extent, like making sure she's got her dextrose when she goes out, and has she got any food or has she got money for food, has she considered that the shops won't be open, blah, blah, blah, and what will she do? - I'm just a terrible nag.

Mothers would sometimes describe trying to make a joke about nagging, although the joke was at their expense:

Malice: She knows I'm a nag and I mean, we make a joke out of it - it's a mother's job to be a nag. I'm not terrible bossy but I am a nag, I do whinge, that's the problem....she's started worrying about her feet [foot care is important for people with diabetes], and she said, "I think I need a really good pair of shoes", and again, I kind of waited for her to be on my side because otherwise I just become a nag.

The word 'nagging' seems to emerge in relation to mothers with teenage children, but why? It appears that mothers and young people are aware of societal expectations that mothers should relinquish power and control, thus allowing their children to move towards independence and autonomy. On the other hand, mothers are still held responsible if problems arise, and in addition, they feel responsible for these problems. Silverman (1987b) states that one way in which nagging can be seen is as the other side of the coin to responsibility, and in this study mothers carried most of the responsibility for young people with a chronic illness.

Segal (1987) argues that because women often have less power in adult relationships, they may express aggression in such relatively powerless ways as by nagging. However, in the context of this research on mothers and young people nagging means something different, and can be seen as one way in which mothers manifest their feelings of responsibility for their teenage children. Nagging can be seen as a less directive, less
confrontational, and perhaps more sensitive way of mothers reminding teenagers about issues, particularly those relating to 'good' control of asthma and diabetes. The implication in many of the interviews seemed to be that the reminding was often unnecessary, and was a problem which related to the mother's 'overanxiety', for which she could be blamed, and could blame herself.

In this way, nagging seems to relate more to the work of Maguire (1992), who links nagging to power, but to the kind of power that operates by controlling women's perceptions of themselves, their awareness of reality. She sees nagging as an example of language being used against women, when in reality, she states: 'what is a nag but a person characterized by her persistence and conviction' (1992: 25). The Oxford Dictionary (Allen 1988) defines nagging as to: 'find fault or scold persistently; worry (person) by nagging; be persistent'. It appears that in relation to this study nagging was seen much more in terms of the first two meanings, as opposed to the latter. However, the latter definition, being persistent, appears to relate much more to what mothers were doing when they nagged. This also supports the work of Ribbens (1994), who reconsiders power in terms of parent-child relations, arguing that in the private sphere the exercise of power might be seen as indicative of caring. However, it is a complex, 'no-win' situation for mothers, which seems to lie at the heart of the autonomy/responsibility conflict. This 'no-win' situation can be illustrated by the following quotes:

Becky: I don't know if I'm a bit of a hypocrite really because I don't like her checking on things and nagging and yet I said to her, "I'd like you to have quite an active role in my blood testing", because that's one area I can see me forgetting to do because it's such a pain rather than anything else....unless she played a role in that I could just quite easily see me not doing them at all, just because I can't be bothered and I don't want it to come to that.

Tracey's mother says:

Mtracey: I can see when she's high - she gets really loud as though she's drunk and really, not aggressive fisticuffs but aggressive verbally. Like, she might say to her brother, "what are you looking at, go away from me, leave me alone", and things like that, and her eyes will get a really glazy look and her eyes get big, so I say, "check your blood", and then she'll start because she's high, and she'll check her blood and it is high and then she'll say, "it's your fault, you told me, you told me to do my blood, it's your fault, you're always nagging" - I don't know how it's my fault.

Cathy describes how both parents, particularly her father, frequently reminded her about her medication when she was younger, although this was not described as nagging:
Cathy: My Dad would say, "I think you need your inhaler, I can hear you wheezing, take your inhaler, have you done your preventer", they were sort of saying, "have you done your night puffer and your morning puffer?"

It may also be that the same actions are perceived differently depending on whether they are done by a woman or a man, and this supports Maguire's (1992) argument that 'nagging' is an example of language being used against women.

From the interviews it appears that nagging is done for two main reasons. Firstly, it relates to mothers' concerns in relation to the 'good' control of illness, which may impact on the future health of their child. Secondly, it relates to mothers' worries about the perceived dangers their child faces in the 'public' world, particularly in terms of diabetes. These two areas will now be discussed.

7.1.4 Future Orientation and Developmental Activity

Concerns expressed by mothers were often linked to their perception of the lack of a future orientation in their daughters and sons, particularly in relation to the long term complications of asthma and diabetes. As previously discussed, Hockey and James (1993) believe this perceived lack of a future orientation to be the crucial factor seen as separating adults from children. However, mothers were again in a difficult position because they did not want to worry their child about future complications, but much of their concern about management, and the resultant nagging, was related to the prevention of future long term complications, particularly of diabetes. Concerns about asthma tended to relate more to sudden death from an asthma attack:

Mben: He isn't looking after himself as he should, but I think as they get to that age they rebel a bit don't they, you know....we've got to the stage where he think's he's alright, and I say, "there's 2000 people that die every year and your age is a very dangerous age because you're not doing it as good as you should be. You're not put on this for fun, if they thought you could come off it they wouldn't be increasing your thing" [inhaler dose], and it's getting it through to him, it's hard.

Mrobert: ....although you don't want to paint the black side all the time, he has to be aware of what could happen to him if he isn't well controlled....you have to let them know that you know. I mean, I wouldn't want him to go through life thinking, "oh, I'm going to be fit and well", because you just don't know, but all this training now, this health and diet and everything is to try and keep him well when he's my age....that's the worst, it's trying to instil in him the future because as I said, he's not interested in what's going to happen next month or next year.
Mjulia: No, I don't think she honestly understands what can happen long
term, to the circulation, the liver and kidney and things, what problems it
[diabetes] can cause your stomach, especially your stomach.....It's because
she's a child and you don't think of what you're going to be like at 40, you
think you'll be ancient if you get that far....My friend, he's got bad feet and
everything, everything you associate with it, with long term high sugar
count, but it doesn't affect Julia. I know one woman who died from it, she
went blind, and she'd had it from age nine [as had Julia], but it just will not
register.

Msimon: I used to, in the beginning, to say to him a lot, "look, you must
have a regular lifestyle if you want to live healthily later on in life". I said,
"we don't want you to die young through complications because you're not
looking after yourself properly". "Oh, yes, yes", but I mean at this age I
think they think you're old once you're 20, don't they? They can't see ahead,
they really cannot see in advance.

The very sensitive and skilled nature of this developmental activity is well illustrated in these
quotes. Mothers are trying to tread a fine line between not worrying their child, but at the
same time making them aware of possible future complications. However, the link between
present control and future complications is not straightforward in either asthma or diabetes,
and both mothers and young people are well aware of this. In relation to asthma, it is
possible to ignore treatment with no immediate adverse consequences, and as Hopper
(1981) points out, diabetes has a 'capricious' quality in that self-management can be carried
out perfectly, but an individual can still develop serious complications.

In relation to a future orientation, mothers also felt that medical staff sometimes lacked
this, concentrating instead on making the young person's life more tolerable now, and this
was particularly the case with diabetes. Mothers were placed in a difficult, unsupported
position, faced with possible negative accusations of being overprotective, over involved,
or nagging unnecessarily. From their point of view it made 'good' control harder to
enforce:

Mjulian: Doctor S said, "oh yes, of course he can have chocolate". I said,
"you know you should be saying no, please say no because I don't want him
to, I don't want him to. I want him to be aware that there can be problems".

Msusan: I have said to her, "look - the whole reason I moan at you and say
that you've got to do this and you've got to do that" - I said, "it's not the
immediate that bothers me, it's if you could do any damage", although Dr T
says there is no real reason to believe that it happens.

Mbecky: The doctors are saying about doing less BM's [test for blood
glucose levels] and I think, I even said to the doctor, to this consultant, "I
wonder if you'd say that if it was your child?" - because again I feel like I don't want to over emphasise this in front of Becky, but I'm thinking in the long term, you know, this isn't like, "there there dear, well tried" - you've got to get it right.

Almost without exception mothers of young people thought that their child lacked a future orientation, and that this was a characteristic of their age which would change as they grew older. This supports the argument of Hockey and James (1993), who believe this perceived lack of a future orientation to be the crucial factor seen as separating adults from children.

As previously discussed, great emphasis is placed on good control of diabetes in view of the need to prevent future complications. However, most young people were aware of these potential future complications, particularly in relation to diabetes. The attitude of young people to a future orientation did not in fact seem any different to the majority of adults who are very aware of what constitutes a 'healthy' lifestyle, and choose to act on some suggestions, and ignore others. However, perhaps because of the almost overwhelming responsibility most mothers felt for the health of their child, much of their care was performed specifically to try to prevent future complications. As previously discussed, this sense of responsibility is a central theme running through much of the work on mothers, caring and health. However, this could bring them into conflict with health professionals, who sometimes implied that mothers nagged unnecessarily. This supports the work of Goldner, who notes that even though health professionals tell mothers not to be so helpful, they rely on their 'ironclad sense of responsibility to get things done' (1985: 41).

7.1.5 Mothers' Responsibility and the Perceived Dangers of the 'Public' World

Mothers also talked about the dangers the 'public' world held for their child, particularly in relation to diabetes. Although this concern had often been overwhelming when the young person was first diagnosed, many mothers still felt very anxious when their daughter or son went outside the home:

Mjemma: I thought of her as having something that was potentially life threatening, you know, like a child who had to sort of go to school and cross very busy roads all the time. I felt that it was like a kind of minefield she was in. It was fine if she was at home because I could check she was OK, but as soon as she left, then was she going to be OK?

Mbecky: ....suddenly I felt so scared to let her out of my sight, really, literally. It was like as scaring as having a new born baby in your hands, but a new born baby that was going to want to go out, it was so frightening. I mean, the first time - there's a shop round the corner, a paper shop - and the first time she went round the corner I was petrified.
Mtracey: For the first couple of years, well, the first year, it was really worrying and I didn't want to let her out of my sight just in case. I wanted her here on time to see her do it [insulin injections and blood sugars], to make sure it was done....I still worry all the time about her. I mean, I even worry about her going to work now on the bike. I say, "don't go on the road, go on the pavement. I don't care if you get nicked on the pavement, you just tell him you're diabetic and you can't go on the road in case you fall off".....you've got to frighten them into reality.

Mharry: I just feel - really, I feel worn out with worry because the minute he goes out the door I'm just worried sick about him.

Mrichard: Well, it's the day by day, or always thinking about it, always on your mind, even when he's out of reach at school - I'm always thinking about him.

By nagging, mothers can be seen to be negotiating a safer public environment for their child, and fulfilling their felt responsibility to care. Much of the worry that mothers expressed appeared to be based on the 'just in case' factor, which seemed to be almost exclusively their responsibility:

Mrichard: Because I have to admit I always say to him, "have you got some glucose?" I don't leave it to him because I know what the consequences are if he hasn't got it when he needs it. It's OK if he hasn't got it and he doesn't need it, but you never know when you're going to need it, because every day is different.

Mtracey: The first time I let her go to Cornwall on her own I thought, "she's got this five hour journey, what if they break down, what if they get delayed and she hasn't got enough food in the car?" So I used to pack this big box of biscuits and crisps and drinks to take just in case, and like, she'd go for the weekend and come back with it, because just in case didn't happen. So she said, "oh my god, you always keep on at me", but it just puts my mind at rest.

As Tracey's mother says, 'just in case didn't happen', and usually doesn't, so consequently mothers are made to feel as if they are fussing and nagging unnecessarily. However, if 'just in case' does happen, and mothers have not taken precautions, mothers are blamed, and blame themselves, because they are seen as responsible. This forward planning and thinking about what might occur is something that many mothers do anyway, but when their child has a chronic illness, the situation is accentuated. It would be easy to describe this sentient activity merely as worry, but the use of Mason's (1996) concept draws attention to the skilled nature of the activity. As Mason (1996) herself points out, conceptualisations of care
which tend to emphasise the physical work of care may underplay the significance of the
gruelling and continuous nature of this activity.

7.2 Mothers As Mediators

Ribbens (1994) states that almost all mothers have to act as mediators between their children
and others, because of the way in which children are viewed as morally incompetent in
contemporary Western societies. She highlights two specific ways in which mothers may
mediate; firstly, by acting as an advocate for their child, and secondly, by acting as an agent
on behalf of wider society to bring their child 'into line' with other people's expectations.
However, she did not examine whether this mediating role is affected by the gender of the
child. This section will concentrate on the first way of mediating, exploring the extent to
which the advocacy role of mothers is gendered.

7.2.1 Gendered Advocacy Role of Mothers

In this study the mothers of sons were more likely to act as mediators because, as will be
discussed in the following chapters, boys were less likely to incorporate their illness into
their everyday lives, and were consequently more likely to hide it, or to not acknowledge it.
In addition, as was seen in Chapter Six, mothers were more likely to be involved in the care
of sons. Mothers negotiated between the 'private' and the 'public' worlds, often mediating
with schools about school trips, sports lessons, or how any sudden exacerbations of illness
should be dealt with. Mothers of boys often instructed friends of their son on what to do if a
problem occurred, as boys were much less likely than girls to do this themselves:

Mjulian: It upset him as well, because his friends used to come here and I
used to say to them, "has he talked to you about his diabetes?", and he'd
say, "don't involve them", and I'd say, "Julian, don't be stupid, you've got
to tell them"....Well, I've told all his friends, and the guys that he's working
with this week know [work experience on building site], just so people
know if he starts doing strange things to put some sugar down him.

Mmartin: I've always said to his friends, when his friends come round here
of a morning, when I go to work I drop them all off, and I've always
explained what to do if Martin's ever not well.

Msanjiv: Until he was about ten, whenever he went to a school fencing
competition I actually drove behind the school bus....the hardest thing was
when he had to go to Holland the first time on a football trip with the school
and I mean, I went to the school and briefed them, you know.

It also seemed that there was an expectation that boys would participate in sport:
Mrichard: They [secondary school] don't seem to acknowledge that he's any different, they expect him to be able to do the things that everybody else does. Well, we want him to do the things everybody else does, but we need to know so that we can prepare him. You've got to eat extra, to do the games, so we need to know. Like the time when he was suddenly sent on a half a mile walk to play games, and he didn't like to say anything, and so we heard about it afterwards which meant of course that we had to write a letter - the first of many.

Mkevin: Especially in the High School, I was always down there and ringing them up. For instance, if he came home and said he had to do rugby in the rain, I used to think, "oh god, out in that weather, you know, there's me trying to keep you from not getting wet". I used to go down there or ring them up, and I suppose they must have thought, "oh god, this woman is absolutely crazy", but it would be me that would have to sit up with him in the night time or get him to hospital, so.... when he was in High School boys that he'd actually grown up with from a young age picked on him because his skin went very bad [eczema], so I went in and sorted that out.

Mothers also talked about how they acted as an advocate for the child within the family, in the 'private' world:

Mrobert: I can see his mood change, I can see the signs I think better than anyone else. I know when he's ill, I've only got to look at him and I can tell straight away if there's anything wrong, I can just tell by his moods how his blood sugar is. So because of that I suppose I see the signs of uproar and I know when to back off and not get too heavy with him about things, whereas I don't think James [partner] does - he doesn't realise sometimes that he's not feeling too good. But on the other hand I don't use it as an excuse. I mean, if he steps out of line he steps out of line, he doesn't get any special treatment or anything just because of his diabetes, and I don't use it as an excuse.

Again, this quote illustrates the sensitive nature of this sentient activity. Robert's mother has to negotiate the fine line between making allowances for him - and persuading others to - because of his diabetes, whilst not allowing him to 'get away' with anything extra by using diabetes as an excuse.

Mothers were far less likely to act as advocates for their daughters in either the 'private' or the 'public' world, which often meant school. Girls were not only more likely to be autonomous in self-management, but as will be seen in the following chapters, they were more likely to be open about their illness in public, so teachers and friends were more likely to know about it:
Lisa: When I first found out I did have asthma it did stop me doing practically everything. I stopped swimming and I stopped doing games and PE.

Int: Did anybody tell you you should stop?
Lisa: No - I just thought if I exercised I'd have an attack.

Lisa gradually started playing sport again, and 'learned her limits':

Lisa: They ask me if I'm feeling OK, and like my netball coach would ask whether I'm well enough to go on court.

Cathy also said that she was quite happy to challenge teachers who did not allow her to use her own judgement:

Cathy: Like, when I did cross country I'd say, "I can't do it", and the teacher would say, "no, you just try" - because you're 12 they're like, "no, do it". So you jog a little way and then you say, "oh, I've got wheezy" - "oh, just try a bit" - and it's like, "no - sorry but no".

These quotes also serve to illustrate the different attitudes to sport held for girls and boys. As previously discussed, sport is seen as very important to the construction of masculine identities, and boys often expect - and are expected - to 'play hard'. The work of Prout (1986) on the gendered meanings of 'wet' children, discussed earlier, is also supported. He found that 'wetness' was seen by teachers and other school workers as a natural female characteristic, an exemplification of the nature of girls, whereas when it was detected in boys it was seen as a threat to their successful transition into manhood. It appears that there was more need for mothers to intervene on behalf of sons, because there were higher expectations that boys would participate in sport. In addition, boys were unlikely to attempt to negotiate with teachers.

As with nagging, mediating can also be seen in terms of Ribbens' (1994) reconsideration of power in line with meanings relevant to parent-child relations. Ribbens highlights the possibility that in the private sphere the exercise of power may be seen as indicative of caring, stating:

the exercise of power might be described as a duty that women are burdened with, which they are obliged to exercise to meet the needs of their children, despite any opposition from their children (1994: 207).

Acting in the role of mediator affected mothers because it could lead to them being accused of fussing, or mollycoddling, although this was not always an overt accusation, but just a
feeling that mothers had. However, Ribbens (1994) did not explore the ways in which gender might impact on mediation and the exercise of power. In this study, mothers were much more likely to feel obliged to exercise power and to mediate on behalf of their sons because of gendered ways of managing chronic illness. Even in situations where mothers of girls felt that they would like to mediate, daughters decided the issue, and often did not allow mothers to mediate on their behalf. It seems that the exercise of power by mothers on behalf of their teenage children is a more complex issue than that described by Ribbens (1994) in terms of young children. In relation to young people, it is the interaction between themselves and their mothers that appears to be crucial.

7.3 Displays of Competence

Both this chapter and the previous one have concentrated on the sentient activity performed by mothers. However, mothers also performed much physical caring activity and the arduous nature of this aspect of care should not be underestimated. Incorporated within these accounts of physical caring activity were quite specific ways of displaying competence which are highlighted in bold in the following examples.

7.3.1 Physical Caring Activity

Many mothers interviewed were eager to describe how they had 'done their best', how they could not have done any more. This often came at the end of a long discussion of the many physical caring activities that they had performed in relation to their child's illness, and these were affected by both the illness and the gender of the child. In the case of asthma, much time and energy went into keeping the levels of dust in the house down. As was previously noted, asthma is often linked with eczema, so some of the physical caring activity relates to this. However, as discussed earlier, girls were more likely to be expected to help with housework, so descriptions of physical caring activities for girls often related to what mothers had done in the past for their daughters:

Mmark: Dust, I mean, I try my best to keep the dust down, I damp dust his bedroom, I hoover the beds, I wash the clothes no lower than 60 degrees.

Mben: I mean, I always put his tablets out for him and he'd take them quite happily in the mornings before he went out to school. I'd do them all, just routine, I just set them all out and then I knew my conscience was clear that he'd taken them....We've paid privately for acupuncture, we've gone to herbalists up town, we've tried everything and spent a fortune and he's not got any relief at all. And the food, the diet, oh my god, no milk, you know, we did all that. We used to go everywhere to try and get goats'
milk because they said do that, and then it was all frozen - you can get it easy now - oh my god, I tell you we have done everything.....Alright, I don't do the bed every day because that's just open, but I'm always dusting everything and hoovering the curtains, you know, and every book, everything. I wash the floor, every single day, sometimes twice a day if he was bad, go and do it just before he went to bed....I still go down and get his prescriptions and things for him, you know, now he's working and whatever, so I can't do a lot more than that.

Mjoanna: She won't let me go to the hospital clinic with her now. But I mean, I did, I did do lots of things to help. Like, I mean, when I moved here, Dr P helped me and we fought with the Housing Trust and they removed all of her floor boards you know, and she's got a new bed now. .....I did everything that the hospital says, you know, non allergic pillows, duvets instead of sheets and blankets and you do all that, you know - I couldn't do any more than what I did.

The examples above illustrate clearly the amount of physical caring activity that many mothers were involved in. However, the type of phrases highlighted occurred so regularly in mothers' accounts that they appeared to be serving a specific purpose. This type of talk is similar to that found in other researchers' accounts relating to the parenting of sick children (Burton 1975; Baruch 1981). Baruch (1981) draws attention to parents' talk in interviews, which he sees as situated accounts constructed to display 'morally adequate parenthood'. However in this study the focus is on why it was mothers who talked in this particular way. It seemed that mothers were frequently trying to justify their actions, so a new category was devised for this particular way of displaying competence entitled 'justification talk'.

7.3.2 'Justification Talk'

This way of displaying competence did not only take place when mothers talked about physical caring activity, but also in relation to other aspects of care. As girls were more likely to be autonomous in terms of self-management, these displays of competence also occurred more often in relation to boys:

Madrian: He decided that he wasn't going to bother to do his injections, and he let himself go to such an extent that he was losing an awful lot of weight and his health was really suffering, so I called the doctor here to see him, and he decided that Adrian needed to be sectioned and put in hospital against his will. There was no violence or fuss, he accepted it, but I don't think it did an awful lot of good, but we tried. I feel as though I've tried sort of everything I possibly could have, you know.

Mkevin: It's me that says that he should be checked by a consultant, it's me that kept pushing and pushing him to actually go down and get it sorted out, other than that he wouldn't have bothered....I actually had to go to
the doctor myself with him and it was me who actually said, "can he actually see a chest consultant?"

In doing this 'justification talk' mothers themselves seem to be judging their own performance against a standard which is almost impossible to reach or maintain, and they appear to be anticipating criticism that they have not done all that they should as mothers. Developing a separate category for this type of talk makes it easier for it to be identified and the meaning explored. As Anderson and Elfert (1989) point out, mothers often feel responsible for having 'created' a child with a health problem, and this can lead to overwhelming feelings of guilt and blame. By talking in this way mothers appear to be defending themselves against potential criticism, and subsequent feelings of guilt and blame. This supports the work of Anderson and Elfert (1989) who state that the 'ideology of competence' is internalised by women, thus perpetuating their role as ultimately responsible for care.

7.4 Conclusions

This chapter has explored the caring that mothers perform in relation to young people with a chronic illness, and the effects that this can have on mothers, by focusing on two key areas, both of which have been developed from the work of Silverman (1987b). Silverman (1987b) draws attention to the effects that the autonomy/responsibility conflict can have on the parents of young people with diabetes. However, this study found that the conflict affects mothers in particular, as they are the parent most likely to be seen as responsible for care. Silverman's (1987b) work did not explore any effects that the gender of the child might have on this conflict, and this chapter showed some of the ways in which the work of mothers was affected by the gender of the young person.

There were three specific ways in which mothers were blamed as a result of being held ultimately responsible for their child's health. Firstly, the mothers of girls were more likely to be blamed for their daughters' poor control, particularly of diabetes. This was often because girls were autonomous in self-management, but this did not necessarily result in 'good' control in the medical sense. The influence of psychological discourse on health professionals was also highlighted, in relation to the emphasis on dysfunctional mothers and poor mother/child relationships (Askilden et al. 1993).

The mothers of boys were in a somewhat different position, because they were more likely to be blamed for 'mollycoddling' their sons. This situation arose because boys were perceived as needing more support in managing their illness, so mothers were more likely to be involved in their care. Husbands were particularly likely to blame their wives for this,
which supports the work of Duncombe and Marsden (1995), who found that men were likely to see women's emotional work with children as unnecessary and debilitating 'fussing'. However, this study develops the work of Duncombe and Marsden (1995), as it was found to be the fathers of sons who were much more likely to voice this opinion. It was argued that this is because 'mollycoddling' strikes at the heart of the social construction of masculinities, threatening the successful transition of boys into 'proper men' (Prout 1986). Mothers could also be blamed by others, including teachers, for not 'mollycoddling' boys when it was thought necessary. This also supports the research of Prout (1986), who found that the sickness claims of boys were likely to be believed by teachers, because of gendered notions that boys were more likely to be 'stoical' in terms of illness.

The third way in which mothers were blamed was for 'nagging', which was previously highlighted by Silverman (1987b) in relation to parents. However, this research found that it was specifically mothers who were accused of 'nagging'. Mothers were very aware that they 'nagged', but in this study nagging seemed to be a way of fulfilling the ultimate responsibility they felt for care, and was done for two main reasons. Firstly, it related to worries about future complications in the case of diabetes, or to a severe asthma attack causing death, in the case of asthma. Young people were generally seen as not having a future orientation, which supports the work of Hockey and James (1993). Mothers could be placed in a difficult position, because they did not want to worry their child about future complications, but at the same time they wanted to try and prevent these. This could also bring mothers into conflict with health professionals, who sometimes implied that mothers nagged unnecessarily, whilst at the same time they appeared to rely on mothers': 'ironclad sense of responsibility to get things done' (Goldner 1985: 41). Secondly, nagging could be seen as a way of mothers attempting to control for the possible dangers of the 'outside' world. The 'just in case' factor was highlighted, which seems to relate directly to mothers' feelings of ultimate responsibility.

This chapter also explored the ways in which the mediating role of mothers is gendered. Mothers of sons were found to be much more likely to act as mediators, both between the 'private' and 'public' worlds, and within the 'private' world of the family. This was examined in terms of Ribbens' (1994) reconsideration of power which she feels may, in the private sphere, be indicative of caring. However, in this research the exercise of power is a more complex issue than was found by Ribbens in her research on mothers with younger children. In relation to this older age-group, it is the gendered interaction between young people and their mothers that is important.
Finally, this chapter explored the ways in which mothers displayed competence, particularly in relation to physical caring activity. This was affected by both the disease and the gender of the young person, with mothers more likely to expect help from girls in these activities. Mothers' displays of competence appeared to form a specific category which has been called 'justification talk'. 'Justification talk' acts as a way of mothers defending themselves from anticipated criticism, and this helps illustrate the extent to which the ideology of competence is internalised by women. It also supports the work of Anderson and Elfert (1989), who argue that mothers of children with a health problem can have overwhelming feelings of guilt and blame.
Chapter Eight

GENDERED WAYS OF MANAGING CHRONIC ILLNESS

This is the first of two linked chapters which explore the impact of gender on ways of managing chronic illness during adolescence, and this chapter explores how the social construction of femininities and masculinities affects the ways in which young people live with asthma or diabetes. Chapter Nine focuses on the consequences that gendered concepts of dependency and responsibility can have for young people, but it should be emphasised that in many ways this is an artificial division, and in reality, these areas are intertwined.

Research which highlights the different effects that illness has for women and men was discussed in Chapter Three, although there has been less research on the ways in which illness impacts on teenagers in gendered ways. It was also noted that until recently, the focus has predominantly been on women in terms of the linking of health disadvantage with gender (Arber 1990). However, as Verbrugge comments:

Wherever germane and possible, results should be obtained for men as well as women. Women's "specialness" (or "nonspecialness", which can be just as informative) can be demonstrated only by gender comparisons (1997: 3).

This chapter begins by exploring the extent to which the teenage girls and boys in this study incorporated asthma and diabetes into their personal and social identities. It will then examine differences in management styles, relating these to the social constructions of femininities and masculinities. The chapter will examine the key issue of 'non-compliance' as seen from the perspective of young people, drawing on the work of Conrad (1985). Conrad (1985) argues that from the patient's viewpoint, altering medication can be seen as an attempt by the individual to assert some control over their illness, and Conrad sees the modification of medicine as 'active self-regulation' rather than compliance. This chapter aims to extend the work of Conrad (1985), by exploring the extent to which ways of self-regulating can be seen as gendered. The last section of this chapter explores the ways in which gendered embodiments can affect the meanings of chronic illness for teenage girls and boys.

8.1 Chronic Illness and Gendered Identities

This section compares the extent to which the teenage girls and boys in this study incorporated asthma and diabetes into their personal and social identities. These identities are based on Mead's (1961) analysis of self, in which personal identities refers to the 'I', or the
self-identity, and social identities refers to the 'me' which operates in the social context. Rather than identity, the term identities will be used in recognition of the fact that there may be multiple identities (Adams et al. 1997). Chapter Three discussed the work of Charmaz, who states that:

''having a chronic illness means more than learning to live with it. It means struggling to maintain control over the defining images of self and over one's life (1991: 5).

Research was discussed in Chapter Three which highlighted the impact that gender can have on the management of illness. For example, Prout's (1986) research on 11 year old girls and boys showed that whereas for girls, illness was seen as something natural, to be expected of them, for boys it was seen as: 'a threat to their successful transition into being proper men' (1986: 131). In addition, Charmaz draws attention to the ways in which chronic illness can: 'relegate a man to a position of "marginalized" masculinity in the gender order' (1995: 268).

This section firstly explores the extent to which gendered meanings of illness affected the ways in which teenage girls and boys incorporated asthma or diabetes into their social identities, and Table 8.1 shows the gender differences found in relation to the young people interviewed for this study.

**TABLE 8.1**

**Incorporation of asthma or diabetes into social identities**

<table>
<thead>
<tr>
<th>Gender &amp; Illness</th>
<th>incorporated</th>
<th>partially incorporated</th>
<th>not incorporated</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Girls with asthma</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Girls with diabetes</td>
<td>8</td>
<td>2</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Boys with asthma</td>
<td>2</td>
<td>0</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Boys with diabetes</td>
<td>1</td>
<td>0</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>21</strong></td>
<td><strong>2</strong></td>
<td><strong>17</strong></td>
<td><strong>40</strong></td>
</tr>
</tbody>
</table>
In this study, the vast majority of girls interviewed were found to incorporate diabetes or asthma into their social identities to a greater or lesser degree:

Alice: Everyone should know because then they can help if something happens. It's not a question of minding or not, it's my health, you know. People, everyone should know so that in case something happens, even if they don't know what to do they can tell someone (diabetes).

Viri: No, I always tell everyone, just in case (asthma).

Some girls were more selective about who they told, but their condition was still seen as part of their social identities:

Reena: I tell my close friends just in case I go and have a hypo attack or something... otherwise I don't really tell everyone. I only - like, I've told my tutor and the year head (diabetes).

Although the majority of girls saw diabetes as part of their social identities, two girls 'passed' selectively under certain circumstances which they perceived as potentially 'discreditable' (Goffman 1963). In Table 8.1 these two girls are categorised as 'partially incorporated', in terms of the relationship of diabetes to their social identities:

Becky: I remember my first date with a boy just after I became diabetic. Like, he would offer me an M & M [chocolate] and there was no way I was going to take one, whereas now it's different, like I might take five instead,...because I think at this age everything is based on being normal, and if you want to appear normal around people for the first time, I think in a certain way, you have to prove you're going to defy it in some way. Like, not seriously, but just at one time having a chocolate from them, so they can see that if you eat sugar you don't just suddenly collapse, which is what a lot of people think.

So although in general Becky had assimilated diabetes into her social identities, in important situations, such as with a new boyfriend, she would make an effort to 'pass', which Goffman (1963) highlights as one of the two main strategies by which people with a discreditable stigma attempt to hide it.

In contrast, the vast majority of boys with diabetes or asthma managed their condition by making it as invisible or as small a part of their lives as possible, particularly in the 'public' world. This invisibility meant that the illness was not seen as an integral part of their social identities, but as something separate:
Int: Do you discuss diabetes with your friends at all, or is it something that never comes up?
Richard: [laughs] No, we don't discuss diabetes at all.
Int: That other boy with diabetes [good friend and classmate of Richard], you wouldn't talk about it with him?
Richard: That's your business if you're diabetic sort of thing.

Jack: It's not what boys talk about really - not being sexist, but that's the sort of thing that girls talk about, problems and things. At school a boy might ask quickly about it [asthma] and I'd say, "oh, it's OK", but they'd never ask questions like what happens when I get it, anything like that....at school it was, "right, I've got asthma, I'll keep it to myself and the people that know, they know, and the people that don't know it won't affect them sort of thing".

The teenage girls interviewed for this study were much more likely than the boys to incorporate asthma or diabetes into their social identities. In terms of the research of Charmaz (1991), it seems that the teenage girls and boys in this study wanted to project different, gendered identities. The extent to which girls and boys incorporated illness into their social identities can be seen as a 'marker' for the differential gendered meanings of illness, and it appears that both asthma and diabetes are seen by teenage boys as potential threats to their status within masculine hierarchies (Charmaz 1995). This helps explain why the boys attempted to make their illnesses as invisible as possible in the public setting, and supports the research of Prout with younger children, in which he found that: ' 'normal' boys were judged against stereotypes of toughness and fitness' (1986: 125), as opposed to girls, for whom sickness was: 'natural and to be expected of them' (1986: 131).

It may also be one reason why the impact of asthma and diabetes was seen differently for the majority of teenage girls and boys:

Jemma: The main thing is that it's [diabetes] always on your mind, so it is a big issue, because you know every certain hour you've got to be doing something towards it, you know.

Reena: It just means you've got to control your sugar level and everything ....I've had quite a few problems with my diabetes because I haven't controlled it very well, and like problems have occurred with my teeth and everything - so, that's what it means to me. You've got to put a lot of effort into it and - it's horrible, it's dreadful, I hate it.

Int: How has it [asthma] affected your life?
Kevin: Not that much I don't think. I still do sports, I'm good at long distance running....after a short time it was all plain sailing really.
Martin: Just plain sailing and not much of a problem [diabetes].

Donald: I just try and forget about it [asthma], you know, put it aside, try and put it aside and get on with things. I don't think it affects my life that much ....I'm not too worried about things.

The quotes indicate that the teenage girls and boys interviewed perceived the impact of asthma and diabetes differently. Whilst the girls appeared to recognise specific problems in relation to living with these illnesses, the boys were much more likely to minimise any difficulties. The fact that these girls accepted being 'asthmatic' or 'diabetic' as part of their social identities, indicates that these illnesses were also assimilated into their personal identities, as part of their 'sense of self'. In contrast, most of the boys did not accept the social identities of having asthma or diabetes, indicating that these illnesses were not reconciled with their personal identities, or 'sense of self'. This is supported by the ways in which girls were seen to think about their illnesses frequently, whilst boys tried to forget about or ignore asthma or diabetes. However, as was shown in Chapters Six and Seven, the mothers of boys were far more likely to be involved in supporting their sons in managing chronic illness than were the mothers of girls. It appears that this support may enable boys to minimise the effects of illness, thus allowing asthma or diabetes to remain outside both their personal and social identities. It is important to stress that this situation is actively negotiated between mothers and young people, and it is this interaction which results in gendered ways of managing.

The following sections explore the ways in which the young people in this study managed their treatment. As discussed in Chapter Three, much of the professional literature on 'non-compliance' is based on the premise that it is deviant behaviour, leading to the apportion of blame directed towards patients (Donovan and Blake 1992). However, this study takes the view of Thorne, who states that non-compliance should be seen as: 'a rational form of social responsibility, consistent with the type of independent health care maintenance advocated for the non-chronically ill population' (1990: 67). Conrad (1985) argues that from the patient's perspective, regulating medication can be seen as an attempt by the individual to assert some control over illness. The four main strategies which people with epilepsy used were identified by Conrad (1985) as 'testing', which involved reducing or stopping medication to evaluate the need for medication; 'controlling dependence', when people tried to reduce their reliance on medication; 'practical practice', when people changed their medication to suit their daily routines; and 'destigmatisation', when people tried to minimise potential stigma by not taking medication in public, or at all. The following two sections will assess whether these strategies were used by young people with asthma or
diabetes, and whether the use of particular strategies was gendered. Firstly, the management styles of young people with diabetes will be explored.

8.2 Management Styles of Young People With Diabetes

Many clinics that young people attend have moved from recommending two injections of insulin a day, to recommending four injections a day, which is said to offer both better control and more flexibility in terms of lifestyle. Table 8.2 shows the gender differences in the number of insulin injections per day that the young people with diabetes gave themselves. Although individual clinic policies may impact on regimes, the difference is marked.

**TABLE 8.2**

**Relationship between gender and number of daily insulin injections**

<table>
<thead>
<tr>
<th>No. of Daily Injections</th>
<th>Girls</th>
<th>Boys</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 injections per day</td>
<td>1</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3 injections per day</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>4 injections per day</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>10</strong></td>
<td><strong>10</strong></td>
<td><strong>20</strong></td>
</tr>
</tbody>
</table>

Six of the girls with diabetes injected themselves with insulin four times a day, which often meant injecting themselves in public settings, such as at school, and in restaurants. This reflected the fact that for them diabetes was seen as part of their social identities. For example, Alice and Jemma are on four injections per day:

Alice: I have to do one injection at school.  
Int: Do you mind that?  
Alice: Well, I mean, I don't mind it any more. I used to, because other people sometimes find it a bit uncomfortable....I mean, it's not too bad now, people accept it, but they used to find it quite uncomfortable, especially the boys, because I just used to sit there and do it.

Jemma: Yes, there was no real problem. I think one girl once said behind my back, "oh, I wish she wouldn't do injections in the lunch break" and I
think that was all, but I knew the other girls wouldn't stand for that so I
don't really care about what people think, you know. In restaurants
sometimes I'll be sitting there sort of stabbing myself and there will be
people looking, thinking, "what's she doing that for?", but I don't care. I
think I'm lucky because I enjoy attention.

Jemma also highlights one of the positive effects that the social construction of femininities
can have in terms of the meaning of illness:

Jemma: Before I'd been terribly bullied and I had a really miserable time at
school, but it improved because people were sort of thrilled by the idea that
they had a friend with a problem and I loved that, I loved the attention of it.

In contrast, of the ten boys with diabetes, nine of them managed by making their illness
and its treatment as publicly 'invisible' as possible, which helped keep diabetes as
something separate from both their personal and social identities. For example, Richard
explained why he chose to manage on two injections per day rather than on four, which
might give him better control:

Richard: I'd have to keep vanishing every lunchtime, and I'm going to have
to take an injection, a syringe into school which will probably get noticed,
and there's not really many places to do it - I mean, the toilets have hardly
got locks on the doors, half of them.
Int: Do you think that would draw people's attention to you more?
Richard: That would, yes.
Int: And what sort of effect do you think that would have?
Richard: I don't know, and I don't want to find out.

Martin is a 15 year old with diabetes who did not say that he had any difficulties in relation
to injections, but his mother told me:

Martin: He won't do them [blood sugars] at school now, he absolutely
refuses, he won't even do an injection at school. He's on three injections a
day and the hospital would like him to go on to four but he won't do it in
front of his friends, and he doesn't like the fact that he is a diabetic in that
respect, he wants to be normal.

Although these boys would not move on to a regime that required treatment in public,
they almost all kept to their prescribed regimes. Of the ten boys interviewed with diabetes,
only Sanjiv did not keep to his regime. This does not include the three boys with 'poor
control' who were not interviewed, who will be discussed later in the chapter. Sanjiv told
me that he frequently forgot his insulin, and rarely checked his blood sugar level. His
mother had been told by health professionals that she should leave Sanjiv to manage his own
regime because of the arguments it was causing, although she found this very difficult. Sanjiv says:

Sanjiv: It's like a constant reminder as well [reason why he does not check blood sugar level]. I suppose in a way the people who do do it, they have more guts and courage because they confront it [diabetes] every single day. I think it's more the fact that I can't be bothered, and it's also the fact that I just want to forget it...and all my life I've always been in every aspect the type of person who can never stick to routine in anything.

Conrad (1985) identified the 'constant reminder' factor as one of the reasons that people alter their medication, in an attempt to destigmatise their condition. He states: 'Taking medication is a constant reminder of having epilepsy. For some it is as if the medication itself represents the stigma of epilepsy' (1985: 35). Although superficially Sanjiv appeared to manage his medication in quite a different way to the majority of boys with diabetes interviewed for this study, in effect they can all be seen to be acting in destigmatising ways.

Conrad (1985) did not explore the impact that gender might have on the meanings of self-regulation, but it seems that in relation to diabetes, boys are much more likely to act in destigmatising ways than girls because of the threat that illness poses to them in terms of masculine hierarchies. Boys made every effort to keep diabetes out of their personal and social identities, attempting to 'pass'. In her research, Charmaz (1991) found that one of the main reasons people attempted to 'pass' was that they believed illness would count against them. However, few boys with diabetes reported actual incidences of bullying, and as with the research of Scambler and Hopkins (1986), in this study it was more likely to be 'felt' (self maintained) stigma than 'enacted' (experienced from others) stigma which impacted on the lives of boys.

Charmaz draws attention to the risky nature of 'passing', and she states that: 'Successful passing often requires an alert assistant' (1991: 69). As was discussed in Chapters Six and Seven, the mothers of boys frequently acted in ways which could be seen as fulfilling the role of 'alert assistant', enabling boys to pass successfully. In terms of mediating, this was often done in a 'conspiratorial' way, and boys were rarely present. In this way, boys themselves were relieved of the task of disclosing and the potential threats that this might pose, and were instead able to maintain a 'conventional' self-presentation.

In contrast, girls were much more likely to incorporate diabetes into their personal and social identities, and this was reflected in how they managed their treatment. The social construction of femininities meant that diabetes was not seen as the threat that it was for boys, and in certain respects, the displaying of diabetes and its treatment could bring
rewards for girls in the form of friendships, as Jemma illustrated. This supports the research of James (1993) discussed in Chapter Two, who found that the friendships of young girls could be structured by: 'the caring-control which, in their future role as adult women caring for dependent others, they are being elsewhere socialised to adopt' (1993: 228). It also supports the research of Prout (1989) cited in Chapter Three, who found that for girls, sickness could sometimes become the focus of intensified friendships. Two girls 'passed' selectively, although diabetes was generally seen as part of their personal and social identities. It would have been very difficult for girls with diabetes to 'pass' to the extent that boys did, even if they wanted to, because mothers were unlikely to be involved in management, and were very unlikely to act as their 'alert assistant'. However, it is difficult to separate out 'cause' and 'effect' in this situation.

8.2.1 Adherence to Treatment Regimes

The following two sub-sections explore the issue of adherence to treatment regimes in relation to the management of diabetes. The term 'treatment regime' refers not only to insulin injections and blood glucose monitoring, but also relates to other factors such as diet, the timing of meals, and regular exercise. Table 8.3 illustrates gender differences in relation to young people's self-assessed adherence to regimes, which in all cases coincided with my own assessment of their adherence. Table 8.3 includes the two young women who responded to my letter in 'Balance', and the three young men whose mothers responded.

**TABLE 8.3**

*Gender differences in terms of adherence to regime*

<table>
<thead>
<tr>
<th>Adherence Level</th>
<th>Girls</th>
<th>Boys</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>'strict' adherence</td>
<td>0</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>'moderate' adherence</td>
<td>6</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>1*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>serious non-adherence</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>1**</td>
<td>3***</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>10 + 2</td>
<td>10 + 3</td>
<td>20 + 5</td>
</tr>
</tbody>
</table>

* Emily
** Louise
***George, Adrian and Harry
The majority of boys interviewed were 'strictly adherent' to their treatment regime, which generally resulted in 'good' control of their diabetes. Keeping to a 'strict' routine in terms of both their regimes and their lives was a key way in which boys were able to keep diabetes 'invisible', and therefore separate from both their personal and social identities. This related partly to the fact that they often managed on two or three injections of insulin per day as opposed to four, which might give them more flexibility in their daily routine. In addition, as discussed in Chapter Six, mothers' care was seen to subtly mute the effects of illness and dependency for boys. This care-giving by mothers was vital in enabling diabetes to be managed by a 'strict' routine, which then allowed it to remain invisible in the 'public' world:

Anthony: I don't think it [diabetes] really affected me that much, it didn't affect me greatly. I was quite happy with it after a couple of days.....I think that the attitude that should be aimed for really is to be able to ignore it in effect, so that it isn't a problem at all, and you can just have an injection in the morning and get on with the rest of your life afterwards....with meal times and things I am probably quite regimented, I eat a specific amount a day at a specific time. I've been living with the same meal times - well, give or take half an hour - for almost 10 years.

In addition, these boys did not appear to have had any thoughts about not taking their insulin, and this again related to keeping diabetes invisible:

Richard: I don't see any point, no, I mean, it would cause more trouble. I mean, if you do an injection how long does it take, two minutes? Don't go and do an injection, how much feeling awful is that going to promote?

In contrast, although six girls with diabetes were on a regime of four injections per day which was designed to give them more flexibility in their daily routine, girls often took this flexibility further than was intended by health professionals. This resulted in 'moderate' adherence to regimes, and generally, 'reasonable' control of their diabetes:

Katie: I don't stick to my diet, I know I don't stick to my diet as much as I should but then I also know how to balance it out. Like, put in more insulin if I'm going to eat biscuits, cakes, or put in less if I'm not going to eat or whatever....often, if I'm going out for a meal, if I know we're going to be going out for a meal, then when I do my injection before that meal, I'll put in extra because I know that I'm going to eat more than I should, or eat a pudding that I probably shouldn't eat.

This greater flexibility of girls corresponds with the strategy identified by Conrad (1985) as 'practical practice', by which people changed their medication practice to suit their daily routine. In addition, because girls were much more likely to be managing independently.
they had more opportunity to experiment. Some girls started experimenting by accident, through delaying a dose of insulin, with the consequent realisation that there were no immediate consequences. This often led to further 'testing' to see just how far their reliance on medication extended, and could be linked with trying to reduce dependency on medication:

Susan: It started off as more of a convenience thing - you know, I'd go to a friend's house, not bother with my insulin and just have it when I got home, but then it slipped and the hours and hours went back and back, and then I used to have it just before I went to bed, and sometimes I'd just completely forget and I'd wake up feeling my blood sugar was high, and I'd have it at like two in the morning and things like that....I sort of found out - when I wasn't giving my insulin, to begin with, I thought, you know, "it's really good" and whatever, but then I realised it caused more hassle than it sort of - as I said, your blood sugar was constantly high and you didn't feel like eating and you were getting into trouble for not eating, everyone was having a go at you for not eating.

The greater flexibility shown by teenage girls supports the research of Charmaz (1995), who found that women showed a 'greater adaptability' to chronic illness than men. It also supports the research of others such as Pond et al. (1996), and Hentinen and Kyngas (1992), who found that teenage girls had worse medical control of their diabetes than teenage boys. In the case of monitoring blood sugar levels, girls were less likely than boys to check them regularly, and they often remarked that they knew their bodies well enough to predict the results without testing. This highlights one of the contradictions of 'guided' self-management previously noted in Chapter Three, in that young people are encouraged to be aware of their bodies, but when it comes to trusting this knowledge, they are told that it is unreliable. In this way, an individual's own experience and knowledge can be devalued in comparison to the information gained from mechanical devices, and the emphasis which health professionals place on these.

8.2.2 Non-Adherence to Regimes

There was also a group of young people with diabetes who reported stopping their medication as far as possible, for varying lengths of time. Only one of the boys in my main sample, Sanjiv, fell into this category. In terms of George, Adrian and Harry, as previously discussed, I was approached by their mothers after placing a letter in 'Balance', a magazine published by the British Diabetic Association. The boys refused to be interviewed, so I only have their mothers' versions of events. These three boys were discussed in Chapter Six, in relation to the high level of concern felt by their mothers for them. Perhaps the clearest explanation of why boys with diabetes might react in this way comes from the mother of George, who wrote:
Mgeorge: The diagnosis of diabetes meant, to George, that he had another weakness to contend with. He was just getting his asthma under perfect control when he became diabetic. He saw it as an imperfection that meant he was not a 'whole' person. It was almost as if he'd developed a physical disability that was instantly visible to others, and he was scared of being teased in the ways he was teased at middle school for being asthmatic....He won't discuss his diabetes with anyone because:

a) he's a very private person
b) he thinks his friends will disown him if they find out he's diabetic as he sees himself as a liability when out with them
c) he finds it hard to control and does not like to admit to not being in total control.

It appears that George perceived the diagnosis of diabetes as stigmatising. Initially he had controlled his diabetes very well, in ways similar to the vast majority of boys interviewed for this study. However, his mother reported that after about one year he had stopped taking his medication as far as was possible, and had become very angry about having diabetes. The importance for George of being in control supports the research of Charmaz (1995), who found a narrow range of credible behaviours for men with a chronic illness, with an 'uneasy tension' existing between valued and disparaged identities. This will be discussed in more detail later in the chapter.

In contrast, girls who stopped their medication appeared to do so at least in part because of the high expectations placed on them by both themselves and others. It was very hard for girls to express why they had acted in this way, but in certain respects it appeared to be a covert way of asking for support. Louise was one of the women in her early 20s who responded to my letter in 'Balance' magazine. Being a few years older than the teenage girls in my main sample, she has been able to reflect back on her experiences. Louise highlights the high expectations she felt were placed on her:

Louise: ....I think if I'd had that kind of, a bit of sympathy it would have made all the difference. I was given I felt none, no sympathy at all, it was all very matter of fact -"all right, let's get this done, let's sort it all out, this is what you've got to do, this is the routine of your life for the rest of your life"- and all this without anyone saying, you know, it's actually tough.

It seems that because of the expectations girls felt to be independent, they were often reluctant to ask for support. However, Louise herself appeared to support gendered ideas about responsibility, stating that in hindsight, she would not have wanted to share control of the practical side of diabetes with others:
Louise: No, I wanted, I did want control of the practical side. I think that was right, because I was eleven and I could handle it, but I actually needed support. I needed to do it myself, but I needed help.

Girls such as Louise found it difficult to ask for help because of gendered expectations that they would be independent and responsible. In contrast to the boys, girls tended to be secretive about their non-adherence, and this will be explored in more detail in Chapter Nine.

To a certain extent these findings contradict those of Miller et al. (1993) cited in Chapter Three, who found that the young women with cystic fibrosis interviewed had all had periods of non-compliance, as opposed to none of the young men interviewed. Miller et al. (1993) concluded that this was because of the social practice of femininity, which included passivity and powerlessness. My research found that some boys also had serious periods of 'non-compliance', but these boys were not obtained as part of my main sample. If I had not placed a letter in 'Balance', I would have reached the same conclusions as did Miller et al. (1993).

This section has explored the ways in which the social constructions of femininities and masculinities impact on ways of living with and managing diabetes. Teenage girls and boys were found to manage in distinct ways which appear to relate to the relative threats that illness poses to the formation and maintenance of femininities and masculinities. The strategies identified by Conrad (1985) were found to be used by young people with diabetes, but the use of the strategies was gendered. Girls were found to use the strategies of 'practical practice', 'testing', and 'controlling dependence', whilst boys used the strategy of 'destigmatisation'. The section will now examine whether the girls and boys with asthma also managed their treatment in gendered ways.

8.3 Management Styles of Young People With Asthma

This section explores the ways in which young people managed their asthma medication, and Table 8.4 (pg.164) illustrates gender differences in relation to taking preventer inhalers.
Table 8.4

<table>
<thead>
<tr>
<th>Take preventer inhaler:</th>
<th>Girls</th>
<th>Boys</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>regularly</td>
<td>9</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>occasionally</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>never</td>
<td>0</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>10</strong></td>
<td><strong>10</strong></td>
<td><strong>20</strong></td>
</tr>
</tbody>
</table>

All of the girls interviewed with asthma were seen to be autonomous in self-management. They had often had a period of experimentation with therapy, but appeared to have 'learned from experience' that they needed their preventer inhalers. In terms of Conrad's (1985) strategies, this could be classified as 'testing the need for medication'. The ten girls interviewed all associated control of asthma with the correct taking of preventive medication. For example, Carol is a 15 year old who has had asthma for the past three years, but it is only in the last six months that she has been taking her preventer inhalers as prescribed:

Carol: When I first started it was OK but then I forgot a couple of times, and then I couldn't be bothered to do it, to try and remember. I thought, "oh no, it's not worth it, I'm alright, you know, I don't need it". But I've found out since I've been taking it that it's helped me.....I know if my asthma really affected me I wouldn't be able to go out with him [boyfriend], I won't be able to do the things I want to do, so I know I've got to take my inhaler to control it so I can carry on and do everyday things I want to do.

Int: How long have you had that feeling of control?
Lisa: It's only lately since I started taking them regularly, since I got back from Birmingham [where she had a severe asthma attack], about the end of August. Now I make sure I take my inhalers every single day.

The regular taking of preventer inhalers indicates an acceptance of asthma as part of the personal and social identities of these girls. In addition, girls were seen to be taking responsibility in relation to their health, which is important in terms of the social construction of femininities. This will now be contrasted with the ways in which the boys dealt with asthma.
The approach of seven of the ten boys with asthma was typified by boys saying that they were growing out of their asthma, and so no longer needed regular preventive medication. All of the boys took their reliever inhaler if they felt they really needed it, but they did not take a preventer inhaler regularly, although it had been prescribed. It was not that these boys denied that they had asthma, but more that they saw it - and made it - a separate, minor part of their lives, by thinking about it as little as possible, and treating asthma as an episodic, acute illness rather than a chronic illness. Consequently boys felt that they did not have to rely on regular preventer inhalers, and in this way, boys were able to keep asthma outside their personal and social identities:

Paul: It's not a case of "no, we don't have asthma so we don't have to take it" or anything, but it doesn't occur to us most of the time because I mean, I can't say that most of my life is ruled by my asthma attacks and that, so until recently I forgot I had asthma at all and then you get your attack and you think, "oh", and then when you're over it you just forget about it. Int: You don't think of having asthma day to day? Paul: No, it's not like diabetes where you have to take your injection every day. My uncle and grandma, they're taking their injections every day, and if they don't they get affected, but if I don't take my inhaler chances are I'll be alright.

Keith: Because asthma just tends to be so episodic and you get lulled into a false sense of security when you don't display any symptoms.

Donald: I mean, if I started to get wheezy then I would take it [reliever inhaler] straight away, I mean, I'm not the sort of person that would say, "oh well, if I don't take it then it will go away" because I know it wouldn't, I know it would just get worse so I'd take my puffers and it would get better.

There were consequences to this gendered way in which boys managed asthma, and some boys did not always feel in control of their asthma:

David: Sometimes I feel that I'm in control but sometimes I feel it's beyond my control, like when I've got a cold.

Int: Do you think you're in control of your asthma? Donald: Yeah, a little bit. I don't, I suppose I don't do everything that you should do - you're supposed to take deep breaths and all that, I mean, I don't really do that. I know I could handle it a bit better from what I do when it comes on, but it's basically down to laziness I suppose, which is stupid.....a lot of times I should sit down and not do anything and I'll go out....I wouldn't let it stop me doing things....if my asthma is going to come on then I've got no control over it, it's going to happen and that's the way it is. I mean, I can't, I do my best to try and stop it but if it's going to happen it will.
Donald, Paul and David had all attended hospital within the past year, for the treatment of severe asthma attacks. However, in contrast to the girls interviewed, this experience had not resulted in the taking of preventer inhalers.

It appears that these boys with asthma are attempting to minimise the effects that asthma might have on their masculine identities by 'passing', just as the boys with diabetes did. The ways in which they did this appear to have little in common with the boys with diabetes, the majority of whom kept to a strict routine with their medication. However, this apparent difference may relate more to the nature of the individual diseases and the threat that each poses to the status of boys within masculine hierarchies. In terms of diabetes, not following treatment can have almost immediate effects, and can soon become life threatening, whereas for the boys with asthma there was a good chance that nothing would happen if they omitted their preventive asthma therapy. It seems that for these boys, control over their personal and social identities as 'normal, healthy males', was more important than controlling potential episodic occurrences of asthma.

In addition, preventive medication may have specific meanings in relation to masculinities. When highlighting the importance of sport in producing culturally prescribed versions of masculinity, White et al. state:

Learning to use the sporting body for boys and men implies also learning to detach oneself from it. As a result, sensitization to bodily well-being and matters of preventive health in general become viewed as the jurisdiction of women and "ambiguous" men (1995: 180).

Whilst the taking of preventer inhalers may be seen positively for girls, in terms of the positive meanings that responsibility and preventive health care have for femininities, for boys it may be seen in a negative way, which can threaten their place in masculine hierarchies. The taking of reliever inhalers may not be perceived in such a negative way, as they can be seen as essential, in much the same way that insulin is for boys with diabetes.

The role that the mothers of boys with asthma played is also important, in that they did not always encourage boys to take preventers. In four of the cases, mothers supported sons - sometimes subtly - in not taking preventers, and this was expressed in terms of concern felt about relying on drugs, and worries about the side-effects of steroids. The mothers of girls with asthma did not discourage their daughters from taking preventer inhalers, but this was partly because girls were much more likely to be autonomous in self-management. In
relation to the three boys with asthma who did take their preventer inhalers regularly, their mothers were very involved in helping with management, in ways similar to the mothers of boys with diabetes.

The meaning of asthma may also be significant. Becker et al. (1993) found that the historical view of asthma as an emotionally-based illness still served to discredit asthma as a 'real' illness amongst both health professionals and patients, and contributed to feelings of stigma. It may be that having any connection with an illness perceived as being emotionally based may be more stigmatising for boys, although no boy expressed this directly to me.

These two sections have compared the ways in which teenage girls and boys live with, and manage asthma and diabetes. In this study, the girls and boys interviewed were found to manage in gendered ways which related to the different meanings that individual chronic diseases and their treatments have in relation to the social construction of femininities and masculinities. The majority of girls with asthma and diabetes were found to incorporate the illness into their personal and social identities, and this was reflected in the ways in which they managed their medical regimes. Girls were found to use the strategies identified by Conrad (1985) as 'testing', 'controlling dependence' and 'practical practice', and this related to the greater adaptability they showed towards chronic illness (Charmaz 1995). Stigma was rarely an issue for the girls in this study, although occasionally girls would try to 'pass' selectively, in front of key people such as new boyfriends.

The majority of boys with asthma or diabetes did not incorporate the illness into either their personal or social identities. They were found to minimise asthma and diabetes by 'passing', which involved concealing the illness and its management as far as possible in the 'public' world. Although superficially, boys' management styles of asthma and diabetes seem to have little in common, this relates to ways of managing different treatments to minimise their potential threat to masculine identities. By far the most important reason that boys gave for altering their medication related to destigmatisation, although the ways in which they did this depended on the condition. As was seen in previous chapters, the supportive role of 'alert assistant' (Charmaz 1991) played by mothers at home, was also vital in enabling boys to 'pass' in public. This section has built on Goffman's (1963) work on stigma, by showing how gender can impact on strategies for dealing with discreditable stigma. It has also extended the work of Scambler and Hopkins (1986) in that the concept of 'felt' stigma was found to be gendered in terms of diabetes and asthma, affecting the lives of boys more than girls. In a similar way, it has extended Conrad's (1985) work on self-regulation, as the use of the strategies identified by him were found to be strongly patterned by gender.
This chapter will now explore how gendered embodiments can affect the impact of diabetes and asthma on young people.

8.4 Gendered Embodiments and Young People

The development of gendered identities includes the development of gendered embodiments and embodied power relations, and as was stated in Chapter Two, Morgan and Scott (1993) believe that rather than simply conferring gender, bodies also receive gender. Morgan (1993) highlights the fact that many studies concentrate on women, because of a tendency to see women as more embodied than men. By examining the experiences of both teenage girls and boys, this research can compare their experiences, looking for differences and similarities. This section firstly explores the effects of embodied power relations, before moving on to discuss the ways in which feelings of control over the body can impact on gendered embodiments.

8.4.1 Embodied Power Relations

In this study, diabetes and asthma were found to impact on embodied power relations in different, gendered ways. In Prendergast's (1996) research on young people in secondary school, she found evidence of embodied power relations such as oppressive behaviours from boys to girls, and from boys to other boys. She found the latter - from boys to boys - very much depended on what she calls 'unfair' characteristics such as body size, over which boys had little control. Richard, one of the boys with diabetes, was noticeably small for his age. When asked if he had been picked on for having diabetes, he replied that he had not, but that he had been bullied about his short height and slight build. As discussed earlier, it was suggested to Richard that perhaps he might introduce a lunchtime injection of insulin to achieve better control and greater flexibility, but he was not prepared to run the risks that this might bring in terms of further bullying. By 'passing' in relation to his diabetes at school, Richard had avoided being bullied for it, but he was unable to hide his short stature. Prendergast (1996) comments that for boys, size, and particularly height, serve to categorise them not just in terms of age, but also in terms of maturity and status. She states that:

Small boys are not just physically immature but judged as immature in all other ways too. They must accept their lower place in the order of things (1996: 10).

This means that status and consequent power is seen to derive not only from what Prendergast (1996) sees as relatively acceptable characteristics such as age, but also from
characteristics which are 'unfair and arbitrary', such as size. For various reasons asthma and diabetes can both be associated with the slowing of growth in children (Salardi et al. 1987). In terms of the different meanings this can have in relation to the social construction of masculinities as opposed to femininities, it can be argued that this particular aspect of chronic illness may impact more on boys than girls, by reducing their status within masculine hierarchies (Charmaz 1995).

Gender differences can be further illuminated when contrasting Richard with Becky, a 17 year old girl with diabetes. Although she felt that verbally, girls might make derogatory remarks about her in relation to her diabetes, she told me:

Becky: Luckily I've always been able to hit back really quickly with something worse. I've always been able to do that, so like, after a while, when they saw things wouldn't affect me and I could get them back so much worse, it's like they either wouldn't want to bring it up in case I cussed them worse, or they just saw there was no point.

It appears that for girls of this age verbal skills are an important characteristic in relation to maintaining one's place within female hierarchies, and can serve to counter any negative impact which might result from having diabetes. Although Richard was verbally one of the most articulate boys interviewed, this appeared to count for nothing - or perhaps even counted against him - within male hierarchies, where physical stature was much more important. Becky goes on to speak about the ways in which she feels gendered embodiments may relate to the differential impact of diabetes on teenage girls and boys:

Becky: I think it's probably harder for men....for diabetic boys it's probably the fact that they have more to prove to the world....Because girls and men have different things to prove, and I think a lot of the time with men they have to prove things further, and like they have to prove they can drink and go unconscious, they have to prove they can fight, they have to be into sports whereas girls don't have to be. I mean, they still have things to prove but I think it's different. Girls, the way I see it is that girls have to be attractive, they have to prove that they can get loads of men, and they have to prove that they are feminine, and all those things you can do - diabetes doesn't really affect it although it tends to become a part of it. Like boys, of course it comes into it, like being attractive to girls and getting girls, but I think there is also the more physical side of it, the fighting and things like that, and boys can't - I don't think boys can be seen to care about things so much like their health or things like that, whereas the way society is girls are supposed to care more about their appearance and like, being healthy...but then, how do you know, maybe if I was a boy I'd see it as harder for a girl.

So for Becky, verbal skills, being feminine, and being attractive to boys are key ways in which she can maintain her place within female hierarchies, and these are less likely to be
affected by diabetes than the factors that she identifies as important for boys. She also highlights caring for one's health as being a feminine attribute, as opposed to boys, for whom it can be seen in a negative way.

In a similar way, the impact of asthma can be seen to have gendered implications in terms of gendered embodiments and embodied power relations. Mark was a boy with asthma who had been bullied about his short height, which was thought to have been partly caused by asthma medication:

Mark: No, I wasn't picked on for my asthma, it's just my height, but when they say that I just don't bother any more because I've heard it all before and I don't care.

This sub-section has explored the physical processes involved in the gendered impact that diabetes and asthma can have on embodied power relations. Both diabetes and asthma affect embodied power relations in different ways, although the particular issue focused on, namely small body stature, appeared to pose a greater threat to male embodied power relations. However, there are other issues which may affect girls more, such as the importance of being slim, and this will be discussed in Chapter Nine. These perceived threats to embodied power relations are also age-specific, as small body stature can be seen as a particular threat to teenage boys, whilst being slim is of great importance to teenage girls. The next sub-section explores the ways in which feelings of control over the body can impact on gendered embodiments.

8.4.2 Gendered Embodiments and Control of the Body

The work of Saltonstall (1993) was discussed in Chapter Two when highlighting the gendered meanings that health has for adults. He found that men associated healthiness with being in control of their bodies, and tended to speak about their bodies as though they belonged to them. In contrast, women spoke about their bodies as though they had a momentum of their own. He also found men to be far more concerned than women with the body as a medium of action, with the function and capacity of the body seen as crucial. This sub-section will examine issues which relate to feelings of control in relation to the body, exploring the gendered ways in which this impacts on young people.

In her research on men with a chronic illness Charmaz (1995) describes how some men viewed their illness as an enemy, and using the work of Goffman (1963), she states that this serves to objectify and externalise illness, thus distancing and separating it from personal, if not social identities. In this study, boys were far more likely than girls to say that they could
control their disease with their mind, although they described this in terms such as 'willpower', and 'being very strong mentally'. This was often linked with viewing illness as their enemy:

Paul: Asthma creeps up on you, it just creeps up on you...a lot of the time I know I'm having an attack, but if I'm playing football I'll say, "now I'll ignore it and I'll play on", yes, and I'll fight through it. I'll say, "look, I know what's happening, I'll take things slower", but you've got to just keep breathing and it goes away, it just goes because of my mental strength.

When interviewing Jasvir, an 18 year old with diabetes, it was noticeable how many times he used the word control in relation to his illness. In relation to any worries he might have about the future in terms of diabetes, Jasvir stated:

Jasvir: I don't worry about it because I know I can control it...No, it doesn't control me - so far I'm winning, I'm winning by a wide margin.

Jasvir described his management of a hypoglycaemic attack in the following terms:

Jasvir: So I just took my glucose, sat down for five to ten minutes, checked my [blood glucose] level, it went up to between three and four and I was OK. Fight it before it gets into you, that's what I have to do.

Similarly, Scott is an 18 year old with diabetes who also sticks to a fairly rigid routine:

Scott: Yes, I control it, I don't let it control me, because otherwise then you just feel miserable. If you're going to sit there and mope around thinking, "oh, I'm diabetic" and everything, you're never going to make no progress. You have to take control of it and do it the best that you can really...I don't neglect myself at all - I don't let it get the better of me and think to myself, "oh, there's no point".

The majority of boys felt that they were in control of asthma or diabetes. Where control was not achieved, as with some of the boys with asthma discussed earlier, blame was placed on the enemy, namely, the illness. In general, boys felt that they had done all that they could.

In contrast, the girls usually expressed a different view, saying that they could control asthma and diabetes as long as they followed the correct regime, so any lack of control was much more likely to be seen by them as their 'fault':

Int: Do you see yourself as having control over diabetes?
Jemma: Yes, I think so, because if I don't have control over it I normally
know why and it's something that I've done. I think it's quite a controllable
thing to have because I know if I eat a chocolate bar it's going to send my
blood sugar up.

Julia: I suppose I'm in control really, like if I wanted to make myself ill I
could but as long as I control my diabetes well, then I'm alright. If my
diabetes is out of control I tend to be ill, really tired and that, but if it's under
control quite well then everything's fine.

Katie: With diabetes you can control it, with asthma it's much more difficult,
and like, it sounds stupid but I think I'd rather be diabetic than asthmatic
because I know what's going to happen depending on what I do, whereas
Amy [sister] with her asthma, she can have an attack any time and not
understand why or anything like that, whereas I can control it.

The girls in this study did not appear to feel in control of their bodies in the same way that
the boys did, and control tended to be associated with following the correct treatment. As
was seen earlier, all of the girls associated control of asthma with the taking of preventer
inhalers. Although the girls did not talk specifically about their bodies as having a
momentum of their own in the same way that the women in Saltonstall's (1993) study did,
the implication appears to be the same. Bodies were seen to need controlling by medical
regimes to prevent a loss of control.

In addition, for the girls stress was seen as a factor making diabetes or asthma harder to
control, and this links in with the idea of bodies having a momentum of their own. Stress
was mentioned as a contributing factor in almost half the sample of girls, but for only one of
the boys, and this ties in with Elliot's (1995) research on asthma, where the majority of
women interviewed assumed that asthma was related to their (in)capacity to handle stress, as
opposed to none of the men. This again supports Saltonstall's (1993) findings, where men
imagined themselves as having 'power over' relationships with their bodies.

This sub-section has found that many of the boys placed a high priority on being in
control of their bodies, and most felt that they had a 'power over' relationship with their
bodies. In contrast, girls did not generally have this type of relationship with their bodies,
and tended to feel that bodies had a momentum of their own which could best be controlled
by medication. Saltonstall's (1993) research involved adults, and this study both supports
and extends his findings to young people. This chapter will now explore both the positive
and the negative effects that these gendered views of the body can have for teenage girls and
boys.
8.4.3  Differential Effects of Gendered Views of the Body

Charmaz (1995) highlights the ways in which the social construction of masculinities can be both beneficial and problematic in terms of illness management. She argues that although traditional assumptions of male identities can encourage men to recover from illness, these assumptions can also lead to a narrow range of 'credible' behaviours for men: 'an uneasy tension exists between valued identities and disparaged, that is, denigrated or shameful ones' (1995: 286). The quote of Jasvir below illustrates clearly the 'two-edged sword' that Charmaz is referring to:

Jasvir: I have to accept it [diabetes], I have no choice have I? I have to accept it but I just don't, I don't want to give up. If I accept it I know it's going to pull me down with it. I'll feel tired and weak and I just don't want to do any exercise, but at the moment I'm not accepting it. I'm just thinking I'm like everyone else and like, enjoy life to the max, and I can exercise and do whatever I want, so I'm not going to accept it yet. If my legs are killing me and I can't stand up for very long I still have to go out, I have to keep my social life going. I can't just back out of it at the very first sign of pain, so you have to go through pain to actually get on top of it. Push yourself to the limits but don't overdo it.

Jasvir told me that he is regarded by his doctors as having 'near perfect control' of his diabetes, and to a large extent this must be due to his determination to fight diabetes, which can be seen as a positive effect of the social construction of masculinities. However, it should be pointed out that in common with the other boys with diabetes, the mother of Jasvir was very involved with and supportive of her son and his treatment. On the negative side, the life of Jasvir is very affected by his constant battle with diabetes, and Jasvir himself refers to some of the consequences he perceives if he begins to lose 'the fight'. The 'uneasy tension' between valued and disparaged identities to which Charmaz (1995) refers is clear, and Jasvir does not appear to perceive anything in between.

In contrast, girls showed a greater adaptability towards asthma and diabetes. In some ways, this can be seen as a positive effect of the social construction of femininities on illness. Charmaz (1995) found that adult women with chronic illness showed a greater adaptability to illness, and were far less likely to attempt to recapture their past selves once they had defined physical changes as permanent. In relation to asthma, girls were more likely to report that they took their preventer inhalers regularly, and this may have helped prevent the severe attacks that some of the boys with asthma had suffered. However, this acceptance of illness could also be seen to have potential negative effects, in that girls could lower their expectations for themselves. Here, Carol describes how she has learned to adapt her life to asthma:
Carol: I realise now I've got to get on with it, because I can't get rid of it, it's not as easy as that, so I have to learn to live with it....if I take it easy then I can do things - it can't - won't stop me from doing anything as long as I'm careful....I won't give up, I still do some sport and hopefully, one day I will be able to run again. When I first got it, I said to my Mum, "I'm not going to stop doing what I want, I don't care about asthma, it's not going to change my life" and it has, you don't realise how much effect it does have. When I look back I realise how stupid I was to just think I could carry on in life.

As was seen earlier, the more flexible approach of girls with diabetes could result in poorer medical control of diabetes than was found in boys.

This sub-section has shown that gendered embodiments can have both beneficial and detrimental effects on the ways in which young people live with diabetes and asthma. The majority of teenage boys felt that they were in control of asthma or diabetes, which came from having a 'power over' relationship with their bodies. They tended to see illness as an enemy to be defeated, which meant that if they lost control, boys tended to blame the 'enemy' of asthma or diabetes, rather than themselves. The work of Charmaz (1995), which highlights the ways in which the social construction of masculinities can be both beneficial and problematic for men, is equally true for teenage boys. There is a narrow range of credible behaviours for boys with chronic illness, with a tension between valued and denigrated identities. Boys with a chronic illness may slip between the two extremes of managing well to managing very poorly, and this would help explain the boys with very poor control whose mothers I interviewed, but who refused to be interviewed themselves. Returning to the traditional assumptions of male identity highlighted by Charmaz (1995), in terms of 'an active, problem-solving stance', and the 'emphasis on personal power and autonomy', teenage boys are very much supported in achieving these goals by their mothers, although boys tended to be unaware of this.

In contrast, the majority of teenage girls felt that they could only control asthma or diabetes if they kept to the recommended medical regime, seeing their bodies as having a momentum of their own. Stress was seen as a contributing factor making chronic illness harder to control in almost half of the girls. In many cases girls had been told this by mothers or by health professionals, which indicates that there is a more general acceptance that the bodies of girls have a momentum of their own. Girls showed a greater adaptability and acceptance of asthma or diabetes, which gave them a wider range of credible behaviours, with less tension between valued and denigrated identities (Charmaz 1995). However, this acceptance of illness could also have negative effects, as girls sometimes lowered expectations for themselves, or in the case of diabetes, achieved a lower level of control than boys.
8.5 Conclusions

This chapter has explored the ways in which gender can impact on living with chronic illness during adolescence. The girls interviewed were far more likely than the boys to incorporate asthma or diabetes into their personal and social identities, and it was argued that this was because of the potential threat that illness can have for the status of boys within masculine hierarchies. The impact of chronic illness was also seen differently, with girls generally recognising problems in terms of living with illness, whilst boys were much more likely to minimise any difficulties.

The chapter examined the ways in which young people managed their treatment regimes, using the work of Conrad (1985), who views the modification of medicine as active self-regulation rather than non-compliance. Conrad's strategies were found to be useful in terms of this study, supporting the generalisability of the typologies which he derived from people with epilepsy. However, in this study the use of the strategies was found to be gendered, with girls much more likely to use the strategies of 'testing', 'controlling dependence' and 'practical practice', which related to flexibility, and boys using strategies relating to destigmatisation. Boys with asthma or diabetes were found to minimise their illness by 'passing', which involved concealing asthma or diabetes as far as possible in the 'public' world. Although superficially the management of asthma and diabetes by boys seemed to have little in common, it was argued that this related more to ways of managing different treatments to minimise their potential threat to masculine identities. As was shown in previous chapters, the supportive role of 'alert assistant' (Charmaz 1991) played by the mothers of boys at home was seen as essential in enabling boys to 'pass' in public, and therefore in minimising the potential threat to their status within masculine hierarchies. However, this help was rarely recognised by boys. This study has built on Goffman's (1963) work on stigma by showing how gender can impact on strategies for dealing with discreditable stigma. It has also extended the findings of Scambler and Hopkins (1986), in that the concept of 'felt' stigma was found to be gendered in relation to asthma and diabetes, affecting the lives of boys far more than girls.

The chapter then explored the ways in which the development of gendered identities could be affected by gendered embodiments, focusing firstly on embodied power relations. Both diabetes and asthma have a gendered impact on embodied power relations, and these perceived threats to embodied power relations were also seen to be age-specific. This section explored the ways in which gendered embodiments can impact on ways of managing chronic illness, looking specifically at feelings of control over the body. The majority of
boys felt that they were in control of their bodies and their disease, and this was often associated with viewing either asthma or diabetes as an 'enemy' (Charmaz 1995). Where control over the illness was not achieved, boys tended to blame the 'enemy' of asthma or diabetes rather than themselves. In contrast, girls did not appear to feel in control of their bodies in the same way, and control of diabetes or asthma tended to be associated with following the correct treatment. Bodies were seen to have a momentum of their own which needed to be controlled by medical regimes. This supports and extends the work of Saltonstall (1993) to teenage girls and boys.

It was argued that the ways in which the social construction of femininities and masculinities impacted on illness management could be both beneficial and problematic. For boys, there was a narrow range of credible behaviours when managing chronic illness, with an 'uneasy tension' between valued and denigrated identities (Charmaz 1995). Girls were found to show a greater adaptability towards asthma and diabetes, which gave them a greater range of acceptable ways in which to manage chronic illness. However, this greater acceptability could also have detrimental effects, as girls sometimes lowered expectations for themselves, or in the case of diabetes, achieved lower levels of blood glucose control than boys. By focusing on both girls and boys, it has been possible to compare and contrast the ways in which gender and age impact differentially on chronic illness management.
Chapter Nine

GENDERED DEPENDENCIES AND RESPONSIBILITIES?

This chapter, the second of two linked chapters exploring the gendered ways in which young people manage chronic illness in their lives, will focus on the impact and consequences that gendered concepts of dependency and responsibility can have for young people with a chronic illness. The previous chapter focused on gendered management styles, but it should again be emphasised that in everyday life these areas are very closely intertwined, impacting on each other. In addition, factors relating to mothers which were highlighted in Chapters Six and Seven will be discussed where appropriate, reflecting the inter-relation of all these areas.

This chapter firstly examines the extent to which there are gendered expectations in terms of responsibility for self-management. Next, the ways in which this impacts on the negotiation of responsibility for self-management in relation to asthma and diabetes will be examined. The chapter then explores the effects of gendered notions of dependency and responsibility, drawing on the work of Silverman (1987c) which was discussed in Chapter Two. Silverman (1987c) observed consultations between doctors and adolescents with diabetes, describing how, once the patient had been defined as an active decision-maker, she or he gained autonomy at the expense of being held morally responsible for her or his actions. He concluded that the production of feelings of guilt was used as a subtle means of control when young people were granted autonomy. However, Silverman (1987c) did not highlight any gender differences, and this study aims to extend his research by exploring the impact of gender on these issues. The issue of gendered guilt will be discussed in relation to two key areas; firstly, diet, which is crucial for the control of diabetes, and secondly, exercise, which is seen as important for the control of both diabetes and asthma.

9.1 Responsibility for Self-Management

In Chapter Six, mothers and health professionals were shown to have gendered views in terms of young people's self-management abilities, being much more likely to see girls as being independent and responsible both in general, and in relation to disease management. This supported the research of Hill and Zimmerman (1995), who found that the mothers of sons with sickle-cell disease invested more effort in their care-giving than did the mothers of daughters. However, Hill and Zimmerman did not interview the young people themselves.
This section will extend the work of Hill and Zimmerman (1995) by assessing the level of agreement found between mothers and young people when interviewed separately as to the amount of responsibility taken by young people in terms of self-management.

Of the 19 pairs of mothers and daughters interviewed, and the one father and daughter, there was unanimous agreement between parent and daughter as to the amount of responsibility girls took in relation to self-management. For example, Julia is 15 years old and has diabetes:

**Julia:** She was just nine when she was diagnosed... she was on a drip for a few days, and from then she's done her own injections, from the beginning - she'd rather do it herself than have anybody else do it for her... her blood sugars she's been totally responsible for since about 11... and from when she was 13 I haven't been going to clinic with her.

**Interviewer:** When did you start going to appointments on your own?
**Julia:** Two years ago, three years ago... my Mum was at work and it's hard for her to get time off so I just said, "Alright, I might as well go on my own". There's like no point her being there anyway, it's easy for me to go on my own.

**Interviewer:** So that was when you felt you could be completely responsible for your diabetes, from then?
**Julia:** I was always responsible for it but Mum just came to find out what was happening, make sure everything was alright.

However, in the 20 pairs of mothers and sons, 13 boys appeared to overestimate the responsibility they took for self-management when compared to the assessment of their mothers. For example, Mark has had asthma from the age of seven years, and is now 18 years old:

**Mark:** No, I do it all myself, take it when I need it - that's my ventolin [reliever inhaler], but with my becotide [preventer inhaler] I just take it in the morning and at night, and if I'm on my own and my asthma gets worse I just have the nebuliser because I know what to do and that.

**Interviewer:** Right, so how long have you known how to manage it yourself?
**Mark:** Always, I've done it myself right from the beginning.

**Interviewer:** When did he start doing that?
**Mark:** I can't remember, I'm not sure, it might have been a year, maybe longer.

Kevin has had asthma from the age of two years, and he is now 18 years of age:
Int: When did you start taking responsibility for your treatment - can you remember?  
Kevin: When I was younger - I can't really remember - I always used to take it myself, you know, whenever I felt really ill or whenever I was meant to take it I always took it. I can't remember it that far back really, it's so natural, you know.

Mkevin: At one stage he was taking quite a lot of tablets as well as his inhalers, and I always used to, you know, make sure he had them in the morning. I’d lay the tablets out in the box they give you - so many sections to put your tablets in - and then I'd put in enough for the day, plus his inhalers, and say to him, "right, you've got to take this one before you do PE", and I was always going on....and I did that virtually all the way through High School, and obviously once he left High School and started working that was different.

One explanation for this discrepancy could be that the mothers of sons underestimated what their sons did. However, this seems unlikely because mothers could describe in detail which tasks they themselves performed, or when these had been taken on by boys. The most likely explanation seems to be that many of the boys interviewed underestimated what their mothers did for them, and overestimated their own role in self-management. There are many possible reasons for this, but one explanation relates to mothers' gendered views on the nature of dependencies. As was shown in previous chapters, one of the consequences of this was that the mothers of boys appeared to subtly mute the effects of illness and dependency by performing often 'invisible' sentient and physical activity, and acting as an 'alert assistant' (Charmaz 1991). This manifested itself in various ways such as adjusting the diet for those with diabetes, or in the case of asthma, it could be physical activity such as keeping the house and particularly the bedroom dust-free. It appears that mothers were so skilled at making these activities invisible, that often boys did not realise what was being done on their behalf. It can tentatively be argued that boys obtain the power and status of feeling autonomous in self-management, without the consequences which girls may experience, and this will be explored in more detail later in the chapter.

This section has extended the work of Hill and Zimmerman (1995) by incorporating the views of young people. Although mothers in this study did invest more effort in care-giving for boys, the boys themselves often appeared unaware of this. However, the denial of dependence by teenage boys may also relate to the meanings that dependence has for masculine identities. As Lees states: 'Masculine identity is constituted in opposition to everything feminine. It involves denial of dependence' (1993: 306). The gendered meanings that dependency has for young people themselves will be discussed in the following section.
9.2 Negotiation of Responsibility for Self-Management

This section explores how young people negotiated responsibility for self-management. In this study the concepts of dependency and responsibility were found to impact on each other, since the notion of responsibility can be linked to the idea of learning to care for oneself. Following Silverman (1987c), independence and responsibility are seen as prerequisites of autonomy. This section aims to explore whether the concept of dependency has a gendered meaning for young people, thus impacting on the ways in which responsibility is negotiated. As discussed in Chapter Two, Green and Hart (1996) found that girls were much more likely than boys to present themselves as responsible, and in this way created gender appropriate identities and gendered notions of responsibility. Also discussed in Chapter Two was the work of Arber and Ginn (1991), who argue that various forms of dependency are gendered and differentially evaluated by society. This implies that being dependent on others for domestic/caring services has a different meaning for women and men, and by implication, for teenage girls and boys. The discussion in this section will extend the work of Arber and Ginn (1991) by exploring whether the differentially gendered notion of dependency found in adults also operates in relation to young people.

The majority of girls in this study appeared to take the initiative in terms of responsibility for self-management, often after little if any negotiation with mothers. It was hard for girls to express why they had taken on this responsibility, and the impression given was that this was just a 'natural' situation, and not a conscious decision. However, it seems that girls were often sensitive to the expectations of others, including parents and health professionals. For example, Susan talks about the time she gave herself her first injection of insulin when newly diagnosed at the age of eight years:

Susan: I can remember it being difficult because I had my arm in plaster [due to a fall], so I can remember it being difficult. I can remember, I was getting quite a lot of attention at the time, you know, everyone saying, "well done", and I was feeling quite chuffed with myself.

As previously seen, Susan's mother describes how health professionals had high expectations of Susan's ability to manage:

Msusan: I have never once given her an injection from the age of eight - she has always refused any help, and I used to think that maybe sometimes this was far, far too much for her. It was [from the medical profession], "it's your diabetes Susan, you're in control, you've got to handle this, and you'll be responsible", and I mean, she just sort of took this on board and that was the end of it.
Similarly, Jemma says:

Jemma: I've always dealt with it myself and I thought that was important because otherwise how was I going to cope when I was older, and I felt more confident if I knew what I was doing, and if I took charge then I could understand, and people - I think the doctors and the nurses respected you more and so they gave you more time....I suppose I do cut her [mother] out really and I just control it myself....As soon as I got diabetes I think I aged two years because, you know, you have to be responsible.

There could also be a desire by girls to lessen the impact of their illness on the family. In explaining why she had taken responsibility for self-management, Katie said:

Katie: Mum didn't ever want to be in control of it, she's always wanted me to be the one to cope with it because she's not going to be there all the time is she?.....she decided, like we all decided it wasn't going to affect family life, my life, anything like that, which meant I would have to be the one in control of it because otherwise, naturally, it would affect everybody.....I didn't want her [mother] always to take the responsibility, I didn't want her to be the one in control of it so I used to prove to myself that I could do it and get on with it myself.

It appears that these girls are responding to the gendered expectations of both themselves and others in relation to being responsible for self-management. Louise is now aged 21 years, and reflected back on when she was first diagnosed as having diabetes at the age of 11 years:

Louise: My Mum told me recently that the hospital stressed very much that my parents, they needed to let me have control because I wasn't young enough for them to need to do my injections or anything like that. I was old enough to be able to do all the stuff myself, so they really encouraged my Mum to take a back seat, which is something I never knew at all..... as soon as I came out of hospital it was all down to me. We went straight on holiday and I remember I was given insulin and it ran out because I had no idea how long a bottle would last or anything. We went on holiday to Ireland and I ran out during my holiday, and my Mum went mad at me and I think that I really just felt that it was my problem, you know, I had to be responsible for it. It was all my fault, it was a real trauma trying to find a hospital....but I also felt that I was old enough, in a way I felt I was old enough to handle it all. I felt very adult then.....I was always told I was serious as a child and sensible and grown up and everything, and I think part of the reason why they left it to me was because they thought I could handle it, and I showed that I could in a way on the outside, but on the inside - the emotional side I didn't cope with at all, I didn't really start coping until I left home.
Louise shows graphically how the gendered notions of responsibility held by health professionals and her parents affected her, and hints at the problems this created for her. When she was 13 years old she started abusing alcohol, and her diabetes was very poorly controlled for about four years.

It appears that parents and health professionals operate with gendered expectations of responsibility in terms of girls. In many situations, girls are more likely to present themselves as responsible (Green and Hart 1996), and it seems that any subtle expectation that girls can and should be responsible for self-management serves to reinforce girls' own feelings of responsibility. It appears that by taking on the responsibility for self-management, girls initially earned praise and gained status from pleasing others. This praise was important to girls, and was cited as a key reason for taking on self-management. However, within a short time competent and 'invisible' self-management was routinely expected of girls, and this could lead to blame, or to girls feeling guilty if self-management was not undertaken as expected. For example, Alice says:

Alice: I was in the netball team and because one time I forgot my snack and I had a hypo and stuff, and from then, ever since then she's [teacher] like been, "oh, she's not, she hasn't got it together enough". You can't afford to make mistakes if it's vital to something, even if it's just a netball match or something, because it gives people the wrong impression....I mean, if I have a hypo it's blamed purely on me.

These consequences of guilt or blame will be explored in more detail later in this chapter.

In contrast, as was seen in Chapter Six, mothers of boys were more likely to describe having to actively - but subtly - encourage their sons to take on more responsibility for self-management, although in general the boys themselves felt that they were responsible. Boys with diabetes were more likely to present themselves as responsible than boys with asthma, but this relates more to the differential meanings of both the diseases and their respective treatments. This is in contrast to the findings in Green and Hart's (1996) research, where the majority of the boys appeared almost proud to present themselves as irresponsible. However, their discussions centred around risk taking and accidents which have specific gendered meanings for masculinities. In this study, boys with diabetes were able to keep it out of their personal and social identities by keeping to a strict regime and not taking risks, and this was important for their masculine identities.

In marked contrast to the girls, none of the boys in this study indicated that taking on various aspects of self-management was related to the expectations of others. It appears that this situation was not interpreted by boys as important either in terms of gaining praise or status. Nor was it seen as important in the same way as it was for girls, by others such as
mothers or health professionals. The contrast is clearly highlighted by the mother of 15 year old Martin and 12 year old Anna, a brother and sister who both have diabetes, although Anna was not interviewed because of her age. In relation to Anna who was diagnosed aged six years, her mother says:

Martin: Everyone seemed to make a fuss of Martin because he was diabetic, so when she got it she was quite pleased - "oh, someone's going to take some notice of me", and she went to hospital - "oh yes, I can do my own injections", and the nurses were so pleased with her, but it wore off....she was very much, "oh, this is easy", and then all of a sudden, "well, I've finished with that now, I don't want to do it anymore", and I said, "no, you can't - it doesn't work like that".

So by taking on the injections initially in an effort to win praise, Anna was then expected to continue with them. Their mother told me that Martin, diagnosed aged three years, had only just started doing his own injections when Anna was diagnosed, and this was partly because of the attitude of the health professionals. From her own point of view, Anna's approach was preferable:

Martin: It's horrible [giving injections] because you are the person going to hurt them basically, because it's not a nice thing to do, and as I say, when Anna went in she just done it herself like straight off, and that's a lot better from my point of view, and I think probably from their point of view too.

There were also clear examples showing how gendered meanings of dependency reinforced the gendering of responsibility for girls. This again supports the work of Arber and Ginn (1991), who argue that women may acquire a more subordinate status as a result of dependency. For example, when describing why they had taken control of doing their insulin injections, Becky and Emily said:

Becky: I just felt as though everything was so degrading, like, my Mum sitting next to me injecting me like I really was some sort of little baby or vegetable, and I just got to the stage where I clicked and I just knew I had to do it myself.

Emily: I control my own diabetes and have had total control for a long time. I don't like other people doing too much for me because then I feel like I'm losing control....Earlier in the year I injured my right arm and ended up in plaster....I had to get Mum and my friends to do blood tests for me and help with my injections while that was going on. Although I was grateful for their help I felt embarrassed and that I no longer had control, and that was awful.
Although boys were often helped with various aspects of self-management, this did not lead them to express similar feelings. For example, Mark was one of the few boys interviewed for this study who felt that he did not have any control over his illness, and who saw himself as unhealthy. However, in his quote at the beginning of this chapter it can be seen that despite this, he was able to gain the status and power associated with feeling autonomous in relation to self-management. Again, this extends the work of Arber and Ginn (1991) because it suggests that differential gendered notions of dependency also operate during adolescence.

The findings from this study indicate that in relation to aspects of living with chronic illness girls feel a loss of status, control and power in situations where they feel dependent on others. In similar circumstances, boys appear to maintain status, control and power because the situation is not recognised by them as one of dependence. However this is partly because mothers are very skilled at making their role as 'alert assistant' invisible.

This section both supports and develops the research of Green and Hart (1996). It supports their findings that girls present themselves as responsible, but in this research many of the boys also presented themselves as responsible and independent in terms of disease management. This may relate to the negative implications that dependence has for masculinities, and the fact that in terms of illness management, responsibility is linked with autonomy. This section also supports and extends the work of Arber and Ginn (1991), who state that various forms of dependency are gendered and differentially evaluated by society. In this study the differentially gendered notion of dependency which Arber and Ginn (1991) observed in adults was also found in young people, where the majority of boys failed to recognise the support that they were given by their mothers. It appears that parents and health professionals also operate with gendered notions of responsibility, and this in turn impacts on young people. In general, the girls reacted to this subtle pressure by taking on responsibility for self-management, for which they were praised. It seems that girls were responding to stereotypical expectations of femininities as being self-sacrificing, docile and virtuous (Coppock et al. 1995). Although this was initially rewarded, competent and 'invisible' self-management was very soon routinely expected of girls, by both themselves and others. This supports the research of Prendergast, who found that girls managed menstruation: 'with proper discreetness - in essence total invisibility - in school, and girls blamed themselves if they failed' (1995: 354). This has consequences for girls which will be discussed in the next section.
9.3 Effects of Gendered Concepts of Responsibility and Dependency

When chronic illness involves a medical regime, self-management relies to a great extent on individual adherence to treatment, as was noted in Chapter Three. Self-management usually refers to a responsive regime pre-determined by the health professional, which the 'patient' is then expected to follow at home. In the case of asthma and diabetes, Bytheway and Furth (1996) argue that they are two illnesses which carry a particularly high level of personal responsibility for 'juggling' treatment. However, there is a contradiction in this 'guided' self-management, in that despite the high level of personal responsibility that people have, health professionals maintain power and control through surveillance, and as a consequence, 'non-compliance' and consequent blame may emerge (Posner 1988).

One key difference relating to the ways in which young people managed their medication was that in the case of the boys, their mothers had knowledge of this, in contrast to the mothers of girls, who seldom had knowledge of the medication practices of their daughters. This issue was discussed in Chapter Six, in relation to the impact on mothers of their child's non-adherence to treatment, but in the following section, the focus is on the gendered implications that this has for young people.

9.3.1 'Secret' Non-Adherence

If I had only interviewed mothers for this study I would have concluded, as others such as Hill and Zimmerman (1995) did, that girls are more willing and able than boys to exercise good judgement and self-care. Conversely, if I had only interviewed young people, I would have concluded, as did Miller et al. (1993), that girls are more likely to have periods of 'non-compliance' than boys. These two pieces of research appear to be drawing opposing conclusions, but by interviewing both mothers and young people separately, the overall picture becomes clearer.

In this study, of the 20 mother/son pairs, one boy with diabetes and seven boys with asthma had been non-adherent in terms of treatment, but mothers were always aware of this. As was seen in Chapter Six, the mothers of George, Harry and Adrian were also very aware of, and affected by the non-adherence of their sons. In contrast, of the 20 girls interviewed as one of the parent/daughter pairs, four girls with diabetes and six girls with asthma had intentionally had an often lengthy, and sometimes potentially harmful period of non-adherence to treatment, of which their mothers - and others - were usually unaware. For example, Reena and her mother gave different accounts of Reena's management of diabetes:
Mreena: Before we were very worried, but now we are happy because she manages herself now...she never eats too much sugar...she does blood sugars two times a day - I think it's all going well.

Reena: I don't do my injection sometimes and that's why I get these problems.
Int: What happens when you don't do it?
Reena: My sugar level goes extremely high and I just start vomiting. It takes the whole day - like, if I don't inject today at the end of this day I'd be like weak, I won't want to get out of bed.
Int: So how often do you miss your injections?
Reena: For quite a while actually. Like, one day I'll do it, the next day I won't.
Int: What about blood sugars, do you ever do them?
Reena: Mmmmm - yes. I can't remember the last time I did them.

Reena's non-adherence is potentially harmful to her health in both the short and long term, but her mother was unaware of it. Although Reena was one of the more extreme cases, this was a familiar pattern, and the reasons for this will now be explored.

Discussion around health and illness occurs within a moral framework (Blaxter 1990), and in terms of people with a chronic illness, there is a perceived obligation for them to show that they are doing their best to control and manage it. As was discussed earlier, asthma and diabetes are two chronic illnesses which both carry high levels of personal responsibility in terms of self-management, but power and control are maintained by health professionals through surveillance. As Posner (1988) notes, patients can be praised for independence of judgement, but only where their action is approved of by health professionals. The majority of girls in this study appeared to be autonomous in the self-management of illness, and consequently they were often left to manage alone - indeed, as seen earlier, this autonomy in self-management was usually seen as a 'good' thing, to be encouraged. Therefore, the level of control girls chose to achieve was very much up to them, whereas boys were far more likely to be advised and supported by their mothers.

In terms of diabetes, Pond et al. (1996) found the quality of control of diabetes to be worse in women than men at all ages from the mid-teens onwards, and they suggest that this may be because women have to cope with both diabetes and the care of the family. In relation to asthma, there are similar findings which indicate that women are more severely affected by asthma than men, although the reasons for this are unclear (Skobeloff et al. 1992). However, during the mid to late teen years, one of the reasons for the emergence of these gender differences may be the development of more pronounced gendered management styles.
The ways in which these girls adapted their medication regimes would not generally be seen as them doing their best to achieve control by either health professionals or mothers, and girls were very aware of this, taking steps to hide it. This supports what Silverman (1987a) highlights as one of the problems of the emergence of 'whole person medicine'. He believes that whilst 'social' made medicine appears less authoritarian than preceding models, it may ultimately be more intrusive, because people are forced to choose and then held responsible, and perhaps blamed, for their choices. In terms of the discourses around asthma and diabetes, there is a great emphasis placed on the fact that 'good' control can be achieved with correct self-management, with the possibility of blame if this is not carried out.

This also supports the research of Maclean and Oram (1988), who found that the people they interviewed with diabetes talked about 'cheating' and blame when describing some of the things that they were doing to 'stretch the limits' of self-management. The authors state that cheating has a negative connotation because it implies breaking the rules which have been set down by health professionals. However, viewed more positively, Maclean and Oram believe that cheating can be seen as a way of learning through experimentation, a way of taking responsibility, of finding a balance. It seems that because girls are seen as autonomous in self-management, they have more opportunity to experiment and to be blamed for this if it is identified. In addition, girls are more likely to be adaptable in their approach to living with chronic illness. Indeed, this greater flexibility and adaptability to chronic illness has been identified by Charmaz (1995) as being beneficial to women living with chronic illness. However, in relation to teenage girls adapting their regimes, this was not seen by girls as something to tell health professionals or parents about, in case they were blamed.

This sub-section has explored some of the reasons why the girls in this study often hid the ways in which they adjusted their treatment. Whatever the causes of this secrecy, one of the resulting effects was that many of the girls expressed feelings of guilt and shame which were not expressed by boys, and this will now be discussed.

9.3.2 Gendered Feelings of Guilt

This sub-section draws on the work of Silverman (1987c) who observed outpatient consultations between doctors and adolescents with diabetes. He describes how, once the patient has been defined as an active decision-maker, she or he gains autonomy at the expense of being held morally responsible for her or his actions, stating:
if rewards and sanctions are the means of maintaining discipline with children, then the production of feelings of guilt is a subtle means of control when they are granted autonomy (1987: 213).

However, Silverman's (1987c) work did not analyse gender differences in relation to this issue. In this study, girls generally took responsibility for self-management before boys, and they were more likely to manage without the support of their parents. Following Silverman's argument, it would therefore seem that girls are more likely to be defined as active decision-makers and to gain autonomy, but to be consequently controlled by the production of feelings of guilt, and this will now be explored.

Girls commonly used terms such as 'guilt', 'ashamed', 'embarrassed', and 'letting myself down', when they described alterations to regimes which they felt would not be approved of. This appears to directly support Silverman's work (1987c), but in this study feelings of guilt were only expressed by girls:

Carol: I went to see her [the practice nurse] and she asked me and I said I wasn't taking my inhaler. It sounded like I couldn't be bothered to help myself and I felt a bit guilty sitting there....I felt really ashamed to tell her that I wasn't taking it.

Susan describes problems which arose when she was eight or nine years old, in relation to food:

Susan: I started hiding food....and when my mum found all this food I'd stuck behind books, behind radiators, on top of cupboards....she phoned the diabetic nurse and I can remember, I felt really ashamed because I knew that what I was doing was wrong, but I just did not feel like eating and I knew it was because I wasn't giving my insulin properly....I can remember the diabetic nurse came round and I hid in my wardrobe because I was so embarrassed and I was so upset that I had actually done this.

Katie: Well, you're supposed to do them [blood glucose measurements], well, I'm told one to two per day, but I usually do about three or four a week I'm afraid - well, one every other day.

Reena: I do feel guilty, quite a lot, because I'm thinking, "I've ruined everything". Like, the doctor said I would have been taller but he said because I didn't control it [diabetes] that well I haven't grown that much.

Clare: I'm supposed to do it [blood glucose measurement] once a day but I've got a bit bad lately and I haven't been doing them very often - I'd say I do it once every two days, something like that. I've got to start being good about that.
When attempting to understand why only girls expressed these feelings of guilt in this study, it appears that the reasons are inter-related. Firstly, because of gendered concepts of responsibility and dependency, girls were much more likely to be seen as autonomous in terms of self-management. As Lees (1993) comments, girls cannot behave in 'reckless' or 'selfishly rebellious ways' without infringing what are seen to be the attributes of femininity. Gendered ideas about responsibility meant that girls often managed alone, giving the impression that they did not need any help or support. Consequently, girls saw any alteration in regimes as their 'fault' in terms of the moral responsibility and moral blame that is attached to illness management. In comparison, boys were less likely to be seen as autonomous in terms of management, and aspects of management were much more likely to be shared with their mothers.

It may also be that because of the gendered concepts of responsibility and the ways in which masculinities are socially constructed, boys were affected differently in potential 'guilt inducing' situations. For example, boys who were not taking their preventer inhalers were aware that they were often perceived by medical professionals as 'reckless' or to blame for their symptoms:

Keith: When I was about 14 I had some flu virus and I really didn't feel very well, and I went to the doctor and then I went to the hospital because I thought it was something to do with my asthma, and the doctors were just indignant at the fact that I never took my dose [inhaler] - "well, what do you bloody expect if you don't?".

Paul: The brown one [preventer inhaler] started giving me side effects, so I don't take it now because it made my muscles twitch now and then...one day my eye would be going and my legs would be trembling as well, and I got really nervy.
Int: Did you go back to the doctor at all?
Paul: Yeah, but he said I was being stupid, he was just brushing me aside, he wasn't very happy to hear about anything.

However, boys did not react by feeling guilty in these situations. In contrast, they often appeared to find these encounters quite amusing. In addition, they were more likely to react by explaining their behaviour as laziness, which girls never did. This may relate to the social constructions of femininities and masculinities, in that laziness may be seen as more acceptable for boys than for girls.

In the following section, two specific areas which led to feelings of guilt for girls will be explored. These are issues relating to diet, which is seen as crucial in terms of diabetes control, and exercise, which is important for the good control of both asthma and diabetes.
Diet and exercise were also key factors in young people's assessment of their health, and in mothers' assessments of the health of their children.

9.3.3 The Gendered Impact of Diet

An important issue for girls in terms of feelings of guilt related to gendered ideas around food, diet and body image. The research of Miller et al. (1993) on young people with cystic fibrosis found a very different attitude towards eating, and a difference in eating habits, between young men and women. The young women were found not to eat as much, and not to eat with the same enjoyment as the young men. Miller et al. (1993) point to differential societal expectations of body image and shape, with an emphasis on slimness for girls, which made it harder for girls with cystic fibrosis to eat the large amounts of food recommended. It is recognised that teenage girls are generally more concerned about body shape and weight than teenage boys (Sweeting and West 1995a), and it seems that the emphasis on food and weight in the treatment of diabetes can bring additional problems for girls, because of the ways in which femininities are constructed. As mentioned in Chapter One, Tattersall makes a link between the condition known as brittle diabetes and eating disorders, stating that:

It is possible that our (well intentioned) emphasis on diet as one aim of treatment of IDDM has actually contributed to the problem of eating disorders among our patients (1997: 106).

In this study girls overwhelmingly mentioned poor diet to be the key factor in relation to their more negative health evaluations, and this was often mentioned by their mothers too. This was particularly important in the case of the girls with diabetes, where diet is seen as critical for the control of blood glucose, and girls often talked about feelings of guilt in relation to their recommended diet:

Jemma: I'm on a diet now because I'm eating too much and I want to lose weight. I'm conscious of how much I weigh, and even though I eat, I know I shouldn't be eating so I feel terribly guilty and go and eat some more because I feel guilty, and it's a vicious circle, so I'm not healthy at all.

Reena: Ever since I started secondary school I started eating a lot of fried food and fatty food and all that, and like, now I eat about five packets of crisps every day - five packets of crisps. Sometimes I feel really bad about why I'm eating so much, and then sometimes I starve myself, like, I don't eat anything all morning until it's about in the afternoon sometime - then I scoff....when I'm eating them [crisps], I don't think about nothing, just eating them, but I feel guilty afterwards, after I've finished eating all of them,
and like, I'm sitting there thinking, "why am I doing this to myself?" Then I try and do some exercise, but it's hard work.

However, because girls felt that they should be autonomous in managing their illness, they did not share these feelings of guilt with their mothers:

Msusan: ....we do actually get on quite well underneath it all and I can depend on her doing things, you know, but as long as I don't mention, as I said, I never mention the diabetes or her weight, the two unmentionables, but I just don't know what to do about her weight - she's never ever been as heavy as this.

Int: So you're pretty much in charge of your diabetes then?
Susan: Yes - I think that's probably a bad thing in my case....I think maybe I'm given too much independence so that I do - as I said, when I was younger I did make my diabetes worse, and I do eat whatever I want and all sorts of things, and nobody really stops me.
Int: Would you like someone to?
Susan: I wouldn't now because I'm so used to doing it my way but if they'd - people had been strict with me and had more control over me earlier on, then I think that would probably have been better.

In contrast, none of the boys talked about feelings of guilt in relation to diet and food, despite the fact that they did not always keep to their recommended diet, and the subject was rarely mentioned by boys. A few of the boys linked food with exercise in a positive way, with exercise being used as a way of obtaining food which was not normally 'allowed':

Richard: I know that if I go to the Environmental Centre that's a whole morning of hard work, so I can eat as much as I like, even a huge great piece of chocolate cake....and the more swimming I do, the bigger the chocolate bar I can have afterwards.

The findings of this study support Tattersall's (1997) link between brittle diabetes, eating disorders and young women, although brittle diabetes is at the more extreme end of a continuum of problems related to food and diet. The majority of girls did not have brittle diabetes, but they almost all had difficulties in relation to diet. This also supports and extends the research of Miller et al. (1993), in that as with cystic fibrosis, the emphasis on food for the treatment of diabetes was seen to cause particular problems for teenage girls. In medical literature, girls with brittle diabetes have been described as 'manipulative', 'cheating', 'attention seeking', 'malingering', and 'faking', and Tattersall states that: 'It has repeatedly been observed that patients with brittle diabetes come from dysfunctional families....' (1997: 107). However, it appears that in many ways the focus placed on food and diet for people with diabetes operates in a gendered way, serving to particularly
disadvantage teenage girls in terms of management and control, and enhancing their feelings of guilt.

9.3.4 The Gendered Impact of Exercise

The value of exercise in controlling diabetes and asthma can also be seen to particularly disadvantage teenage girls, who often participate in little sport or exercise (Prendergast 1996). This was a further issue about which many of the girls in this study expressed guilt, as opposed to none of the boys. In addition, this lack of exercise was often seen by girls as a major cause of their perceived unhealthiness:

Becky: No, I don't think I'm healthy but I think that's to do with the fact that I don't do enough sport and I don't eat a healthy enough diet, and that makes me feel guilty.

Joanna: Asthma makes you unhealthy - you can't run as fast, can't do much exercise, aerobics makes you red-faced, it's better not to bother - but then I feel guilty.

In their research on young people with cystic fibrosis, Miller et al. (1993) found young women to be much less physically active, although they all knew that exercise would be good for their health, and the authors concluded that the social construction of femininity for young women does not include a great emphasis on organised exercise activity.

The mothers of boys were much more likely to view their sons' health positively than were the mothers of girls. In the case of both boys and their mothers, health was seen to relate very much to the amount of sport boys played, and almost every boy participated in exercise of some form. Even self-admitted 'non sporty' types who did not participate in the more traditional male sports such as football undertook a variety of exercise such as karate, trampolining, sailing, cycling and swimming. In many cases these activities had been initiated and encouraged by parents to take the place of more traditional sports. Sport was seen to play an important part in maintaining good control of both asthma and diabetes by boys and their parents, but this was rarely the case with girls. In this study, the emphasis on sport was so pronounced that at times it seemed that boys were trying to prove that they were better at it than their 'unimpaired' peers:

Jasvir: Every Tuesday I go to the swimming pool, and Wednesdays and Fridays I do weight training, and if I can't keep to those actual days, I'll make it another day....to look good and feel good I have to go and do it, I feel better.
Scott: If I go too high [blood glucose level] what I would do is, like, I would jog on the spot or something. I do a lot of jogging or running. I run round the house because it's usually at night that it happens. It never happens during the day, and so I run round the house and just use up the energy and then I'm OK.

Int: So you wouldn't give yourself more insulin?
Scott: No, I control it myself. I wouldn't want to give more insulin in case it [blood glucose level] goes down too low. Now I know a safe remedy I'd rather just like wear it off, rather than give myself more insulin.

Martin: Yes, I do see him as healthy, he's very health conscious. I mean, I've got an exercise bike and he'll often get on there of a night. He's got into football in a big way in the last two to three years. He loves all sport, loves athletics and things like that, and he's very aware that he wants to keep himself fit. I don't know if all boys do that at that age, I think perhaps they do.

Int: Do you think that helps him keep his diabetes under control?
Martin: Oh yes, yes, definitely.

Richard: I'm not a very sporty person, and during the lunch times I don't go out and play football or anything like that. I mean, on Mondays I have an hour long badminton lesson, on Tuesdays I have an hour and a half of squash and an hour and a half of judo, on Thursdays I have PE, and on Saturdays I go swimming.....doing nothing is the easy option, and with my diabetes, I ought to do something active of an evening or else I'll do my test [blood glucose level] and it'll be high.

Int: So you use exercise to control your diabetes?
Richard: Yes, and it's fun, especially when the weather's nice. When the weather isn't nice you know you can sit up there in the bedroom on a rowing machine which is dead boring, or you can jump up and down on the trampoline which is more dead boring.

Richard's exercise was closely monitored by his mother:

Mrichard: It's hard work persuading him at times that he should do it [exercise]. He has a walk to school every day and we feel that's good for him because he has to do it, and it's sort of painless exercise....I wonder how much longer he'll want to come swimming with us too, but he certainly needs to do it, and he does squash and judo after school, and then there's the two games days at school, so it's quite a lot in a way, but it certainly is important.

Miller et al. (1993) state that male embodiment involves expressing bodily power and strength through physical activity, and they argue that masculinity in Western society is learned primarily through organised sport. Hewett's (1994) research on adult men with asthma also found a great emphasis placed on sport. White et al. (1995) highlight the particular importance of risky sport and injury experiences for adolescent boys in terms of the transition to adult masculinities, and the importance of the institution of sport which
serves to construct and reconstruct masculinities. They draw on the work of Connell who states:

Sport is, all considered, astonishingly important. It is the central experience of the school years for many boys, and something even the most determined swots have to work out their attitude to (1983: 18).

These two areas of diet and exercise have a polarized gendered impact on young people. Because of the ways in which masculinities and femininities are socially constructed, diet and exercise can both have a negative impact on girls, causing them to feel guilty. In contrast, the issue of diet had little effect on boys, and exercise had a positive impact for boys, because of gendered identities. In terms of Silverman's (1987c) research, this study found that the use of guilt as 'a subtle means of control' was a gendered strategy which only appeared to affect girls. Although guilt sometimes worked in the way that Silverman identified, it more often served the purpose of making girls feel worse about themselves, which led to self-blame. Rather than acting as a 'subtle means of control', it often had the opposite effect of exaggerating the problem for girls.

This also relates to Alderson's (1996) view of adolescence and transition as social constructs, and the effects that this can have. Although girls were seen as 'active decision makers' (Silverman 1987c), the fact that they were also perceived as adolescents in transition to adulthood meant that they had less 'power and decision making responsibility' than adults (Hockey and James 1993). Consequently, although girls were seen to have the prerequisites of autonomy, namely, independence and responsibility (Silverman 1987c), this did not result in a 'real' freedom to make their own decisions. This supports Alderson and Montgomery's (1996) definition of autonomy, in which they separate the capacity to be autonomous from the opportunity to be autonomous, stating that the latter relies on having control over one's life. In this study, girls did not have full control over their lives, and so were not fully autonomous, according to the definition of Anderson and Montgomery (1996). Therefore, treatment which did not follow medical guidelines was hidden from health professionals and mothers, with consequent feelings of guilt.

9.4 Conclusions

This chapter has focused on the impact and consequences that gendered concepts of dependency and responsibility can have for young people with asthma and diabetes. Firstly, it explored the extent to which parents and children agreed on the amount of responsibility taken by young people in terms of self-management. The work of Hill and Zimmerman (1995) was extended by incorporating the views of young people. This study supported the
research of Hill and Zimmerman (1995), in that the mothers of sons did invest more effort in care-giving for boys. However, by incorporating the views of boys this study was able to extend their work, as it found that boys themselves often appeared unaware of this support. In contrast, girls and their parents agreed unanimously about the amount of responsibility girls took in relation to self-management.

The next section explored how young people negotiated responsibility for self-management. The majority of girls were found to take the initiative in terms of responsibility for self-management, often with little if any negotiation with mothers. Girls appeared to be responding to the gendered expectations of both themselves and others, and it appears that parents, health professionals and girls themselves operate within gendered notions of responsibility. In contrast, the mothers of boys were more likely to describe having to actively encourage their sons to take on more responsibility for self-management. This section was able to support and extend the work of Arber and Ginn (1991), in that the gendered notion of dependency they observed in adults was also found in young people. In relation to living with chronic illness it appeared that girls felt a loss of status, control and power in situations where they felt dependent on others. In similar circumstances, boys appeared to maintain status, power and control, because the situation was not recognised by them as one of dependence. This is in part because the care-giving performed by mothers is often 'invisible' care.

Having argued that the concepts of responsibility and dependence operate in gendered ways for young people with a chronic illness, this chapter then explored the effects that these gendered concepts can have for young people in terms of living with and managing chronic illness. One of the key gender differences relating to the management of medication was that the mothers of boys had knowledge of this, in contrast to the mothers of girls, who were usually unaware of how their daughters managed their treatment. 'Secret' non-adherence was quite common amongst girls, but not boys, and this chapter explored the reasons for this gender difference. It appears that many factors combine to produce this reaction in teenage girls. Firstly, the more adaptable ways in which girls live with chronic illness may mean that control is not the top priority for them. However, discussion around health and illness occurs within a moral framework, and people with a chronic illness have a perceived obligation to show that they are doing their best to achieve 'good' control. Health professionals place great emphasis on the fact that 'good' control of both diabetes and asthma can be achieved with 'correct' self-management, with the possibility of blame if this is not carried out. Girls were aware that their ways of managing might not be seen as them doing their best to achieve good control by either health professionals or mothers, and they therefore took steps to hide their medication practices. This secrecy often resulted in feelings
of guilt for girls. In the same situations, boys did not react with feelings of guilt, which may relate to the gendered meanings of responsibility.

Feelings of guilt were a particular issue for girls in terms of food, diet and body image, and it seems that the focus placed on diet in diabetes may disadvantage girls. Perceived poor diet was one of the major reasons girls gave for their low health self-rating. Girls also had feelings of guilt in relation to their lack of exercise, which is seen as important in the treatment of both diabetes and asthma. Lack of exercise was another major reason girls gave for perceived 'unhealthiness'. In contrast, the issue of diet did not appear to affect boys, and for the vast majority of boys the emphasis on sport had a positive impact because of the importance of sport to the social construction of masculinities. For the majority of boys, participation in sport was the major reason they gave for their high health self-rating.

In terms of Silverman's (1987c) research, this study found that the use of guilt as a 'subtle means of control' was a gendered strategy which affected only girls. Although guilt sometimes worked to 'control' girls, it more often had the opposite effect of exacerbating the problem. This relates to Alderson's (1996) view of adolescence and transition as social constructs. Although girls may be seen as 'active decision makers' (Silverman 1987c), and as independent and responsible, they were also perceived as adolescents who did not have 'real' freedom to make their own decisions. Alderson and Montgomery (1996) define autonomy as encompassing both the capacity and the opportunity to be autonomous, stating that the latter relies on having control over one's life. In this study, girls did not appear to have full control over their lives, and according to the definition of Alderson and Montgomery (1996), were not fully autonomous. Treatment which did not follow medical guidelines was hidden from health professionals and mothers, with resultant feelings of guilt.
Chapter Ten

CONCLUSIONS

This chapter draws together and discusses the results of this study within a number of conceptual themes which relate to the initial research questions. It places the study findings within the context of the literature reviewed, evaluating its contribution, and the health policy implications which arise from this study are also discussed. This study has been exploratory in nature, utilising qualitative methods to examine the ways in which the development of gendered identities during adolescence impact on both the meanings and the management of chronic illness, using diabetes and asthma as exemplars. The role of mothers in supporting these gendered ways of managing has also been examined, as has the impact that this work can have on mothers. This study is temporally specific, examining the construction of gendered identities in the late 1990s, during what is commonly thought of as a time of transition. Issues such as self-management have been placed within a historical perspective, but it should be emphasised that the interlinking themes of this study are in a constant state of change. During the course of this chapter, the four research questions posed earlier in the thesis will be addressed, which were:

1) To explore how gendered identities impact on both the meaning and the management of chronic illness, using diabetes and asthma as exemplars.

2) To explore the ways in which the gendered transition from 'dependent' childhood to 'independent' adulthood is related to autonomy in the management of chronic illness.

3) To examine how young people and parents, particularly mothers, negotiate changes in responsibilities in relation to the management of chronic illness, and to explore how this negotiation relates to gendered expectations of independence.

4) To explore the consequences that care-giving for teenagers with a chronic illness can have for mothers, particularly in terms of the difficult dilemma of encouraging young people to be autonomous in self-management, whilst still being held ultimately responsible for any problems which occur.
10.1 Gendered Identities and Chronic Disease Management

10.1.1 The Differential Meanings of Chronic Illness

Charmaz called for comparative research looking at the differential experience of men and women with chronic illness, stating:

"...studying men and women comparatively in conjunction with marital, age, and social class statuses, in addition to the type of illness can substantially refine sociological interpretations of the narratives of chronically ill people (Charmaz 1995: 287).

Although there is little comparative research on the differential gendered experiences of adults with chronic illness, there is even less on the gendered illness experiences of young people. This study shows that young people between the ages of 15-18 years have distinct gendered ways of managing asthma and diabetes and their respective treatments. One of the few studies in this area by Miller et al. (1993) reached the same conclusions in relation to a small sample of twelve young people with cystic fibrosis, and my research supports but extends their findings. Firstly, this research is able to compare the gendered management of two different diseases, and secondly, it explores the key role that mothers play in supporting these gendered ways of managing chronic illness.

Ways of managing were seen to relate to the specific effects that diabetes or asthma and their treatments had on gendered identities. In general, having a chronic illness did not appear to threaten the gendered identities of girls, and consequently they were much more likely to incorporate their illness and its treatment into both their personal and social identities. In contrast, boys were very unlikely to incorporate asthma or diabetes into either their personal or their social identities because of the threats that chronic illness posed to their gendered identities. Consequently, boys were more likely to minimise their disease and any restrictions by 'passing' in the public sphere, although this was often only possible because their mothers put time and effort into helping them manage from home.

Prout (1989) found that sickness had different effects on the friendship networks of young girls and boys. My research findings support this, with teenage girls receiving help from their girlfriends, which Prout claims can be seen as girls rehearsing their adult role in terms of health work. In contrast, teenage boys made every effort to 'pass' amongst their friends, with asthma or diabetes rarely mentioned. However, as with Scambler and Hopkins (1986), it was more likely to be 'felt' stigma which impacted on the lives of boys. Where girls did attempt to 'pass' it was a 'selective' process, usually in specific 'discreditable'
situations such as with new boyfriends. James (1993) found that the 'spoiled identities' of children with conditions such as asthma could jeopardise their relationships, but my study found this to be a gendered situation. Asthma and diabetes could often be seen as advantageous to the relationships of girls with other girls. Boys rarely reported being supported by other boys, but this was partly because they were very good at 'passing', so there was little opportunity. This study builds on the work of Goffman (1963), by showing how gender can impact differentially on strategies for dealing with discreditable stigma. It also extends the findings of Scambler and Hopkins (1986), in that the concept of 'felt' stigma was found to be gendered in relation to diabetes and asthma, affecting the lives of boys more than girls.

In terms of the work of Charmaz (1995), who explored the meanings of chronic illness for masculine identities in adult men, my findings both support and extend her research findings to teenage boys. Charmaz (1995) argues that the traditional assumptions of male identity are a 'double-edged sword' for men with chronic illness, in that they can encourage men to be active and to try to recover. However, she notes that these assumptions narrow the range of credible behaviours for men, stating that: 'an uneasy tension exists between valued identities and disparaged, that is, denigrated or shameful ones' (1995: 286). My research found this 'uneasy tension' to be very real for teenage boys. Although the vast majority of boys interviewed had 'valued identities', a few, particularly those who refused to be interviewed, could be seen to have 'disparaged identities'. Boys in this study appeared to have a narrow range of credible behaviours which related to the meanings of chronic illness for masculine identities. In practice, this resulted in them managing in polarised ways, either very well, or with great difficulty. Charmaz found that for adult men, chronic illness could: 'relegate a man to a position of "marginalized" masculinity in the gender order' (1995: 268). In this study, the few young men who were unable to 'pass' did appear to be relegated to a position of "marginalized" masculinity.

Charmaz (1995) also found that trying to maintain past masculine identity by 'bracketing' illness as something separate from life could adversely affect health. In this study, 'bracketing' had both protective and harmful effects on the health of boys, depending on the illness. In order to 'bracket' diabetes, the majority of boys in this study kept to a strict treatment regime, which usually resulted in good control of their diabetes. However, by 'bracketing' asthma as an acute episodic disease, boys were less likely to take the preventer inhalers which might have prevented severe asthma attacks.

However, threats to gendered identities could also arise from embodied power relations, and these were gender specific. Asthma and diabetes can both be associated with the
slowing of growth in children (Salardi et al. 1987), and in this study, teenage boys were found to have been bullied by other boys for their small stature. This supports the findings of Prendergast (1996), and extends her research into the effects of embodied power relations on chronic illness management. In contrast, it was shown that different aspects were important for teenage girls in relation to keeping their place within female hierarchies, including verbal skills and being physically attractive to boys, which were not likely to be directly affected by asthma or diabetes. In addition to being gender specific, these threats are also disease specific.

In general, girls showed greater adaptability towards both asthma and diabetes. This supports and extends the research of Charmaz (1995), who found that women with chronic illness showed a greater adaptability, being far less likely than men to attempt to recapture their past selves once they had defined physical changes as permanent. However, although this adaptability could have positive effects, it also resulted in detrimental effects for girls. As in the research of Miller et al. (1993), the girls in this study were found to be less positive in relation to their everyday experiences of living with asthma or diabetes. This often resulted in lowered expectations for themselves which this study found was confirmed by others such as teachers. This supports the research of Prout (1986), who found that teachers of 11 year olds perceived sickness as a sign of weakness in boys, whereas for girls it was seen as 'natural' behaviour. For girls with diabetes, greater adaptability could also result in poorer control of blood glucose levels.

10.1.2 Treatment Regimes

Superficially, the ways in which teenage boys managed the treatment regimes of asthma and diabetes appeared to have little in common. However, it was argued that this related more to the ways of managing different treatments to minimise their potential threat to masculine identities. In terms of asthma, boys tended to say that they were growing out of the condition, which meant that they were unlikely to take any regular preventer inhalers. By doing this, they were more likely to run the risk of having to take reliever inhalers for symptoms, or of having a severe attack in the 'public' sphere. However, it appears that for these teenage boys, control over their social identities as 'normal, healthy males' was more important than controlling potential episodic attacks of asthma. In addition, it appeared that the taking of preventive medication had negative meanings in relation to masculinities, which supports the findings of White et al. (1995).

In contrast, diabetes could not be ignored without almost immediate consequences, so boys tended to keep to their prescribed regime quite strictly in ways intended to make the
disease as invisible as possible in the 'public' sphere, thus minimising its potential impact on their social identities. This extends the work of Conrad (1985), who found that some people self-regulated their medication in an attempt to minimise stigma, which he termed destigmatisation. My research findings indicate this to be a gendered strategy. Boys were much more likely to act in destigmatising ways, which relates to the meanings of illness for masculinities. In addition, the way that destigmatisation manifests itself depends on the individual disease and treatment regime.

Green and Hart (1996) found that boys were more likely than girls to adopt risky behaviours, and taking risks is seen as a part of masculine identities, particularly for young men. However, the situation highlighted by this research seems more complex. In this study, boys with asthma were found to take risks with their medication, but this was not the case with the majority of boys with diabetes, who tended to stick to their medical regime. Keeping the disease as invisible as possible in the 'public' sphere was their priority, and it appears that boys of this age act within a hierarchy of perceived threats to their masculine identities.

However, it should be noted here that one of the key limitations of this study was my inability to recruit boys who might be finding the management of chronic illness more problematic. This was partly due to my approach which was to gain my sample via medical gatekeepers, and these boys had often been 'lost' to the system, as they had stopped attending clinic. Having identified some boys through their mothers by advertising in 'Balance' magazine, the next major limitation was my inability to interview them, as they did not want to discuss their experiences.

The ways in which girls managed their treatment regimes reflected the fact that in general, asthma and diabetes were incorporated into both their personal and social identities. In terms of asthma, girls had often had a period of experimentation, or 'testing' (Conrad 1985) in relation to treatment regimes, but appeared to have learned from experience that they needed preventer inhalers to control their asthma. In contrast to the boys, the taking of preventer inhalers could be seen positively for girls in terms of feminine identities, as responsible behaviour. Girls with diabetes were likely to have agreed to a regime of more frequent insulin injections than boys, which usually meant that at least one injection had to be given in the 'public' sphere, usually at school. This regime is said to offer both better control and more flexibility. Girls used the strategies of 'testing', which involved reducing or stopping medication to evaluate the need for it, and 'controlling dependence', when they tried to reduce their reliance on medication. They were also more likely than boys to use the strategy identified by Conrad (1985) as 'practical practice', which related to practical reasons such as
fitting specific occasions into their daily routines. However, although the girls in this study appeared to be using medication in ways which might offer better control of diabetes and asthma, this was not always the case in practice. This relates to the gendered meanings of dependency and responsibility which will be discussed in more detail in the following section. My research findings extend the work of Conrad (1985), as they indicate that the strategies he identified were used in gendered ways by young people, relating to both the meanings of chronic illness and the meanings of medication for gendered identities.

The gendered management of treatment regimes is also linked to gendered notions of control over one's body. Saltonstall (1993) found health to have gendered meanings for adults, with men associating healthiness with being in control of their bodies, and women speaking about their bodies as though they had a momentum of their own. My research findings support and extend those of Saltonstall (1993) into the area of chronic illness and its treatment. My study found that control over the body was also perceived in gendered ways by the young people interviewed. The boys were much more likely to feel that they could control their bodies, and consequently, their chronic illness. This control might take the form of 'using will power' to control asthma attacks, or using sport to help control blood glucose levels in the case of diabetes. Where control was not achieved, boys tended to blame the 'enemy' - asthma or diabetes - feeling that they themselves had done everything possible.

In contrast girls expressed a different view, saying that they could control asthma and diabetes as long as they followed the correct treatment regime, so any lack of control was much more likely to be seen by them as their 'fault'. Although the girls did not talk specifically about their bodies as having a momentum of their own in the same way that the women in Saltonstall's study did, the implication appears to be the same. Bodies were seen to need controlling by medical regimes, or there was a potential risk of them becoming out of control. This links to the way that 'stress' was seen by girls, their mothers, or health professionals as a contributing factor making diabetes or asthma harder to control in almost half of the sample of girls, but in only one of the boys. This supports similar findings by Elliot (1995) in relation to adults with asthma. My research findings support Saltonstall's (1993) work, in that boys were found to imagine themselves as having 'power over' relationships with their bodies, whilst girls saw their bodies as having a momentum of their own, and it appears that these gendered views may be widespread and pervasive.

In Chapter Nine, the ways in which the social construction of femininities and masculinities impact on two specific areas were explored. The emphasis on food and diet in diabetes appears to particularly disadvantage teenage girls because of gendered expectations
around body image and shape, and my research findings support those of Miller et al. (1993) in relation to young people with cystic fibrosis. They also support the tentative links being made by clinicians (e.g., Tattersall 1997) between young women, 'brittle' diabetes and eating disorders, although 'brittle' diabetes is at the extreme end of a continuum of difficulties with food and diet. In this study, girls overwhelmingly mentioned poor diet to be the key factor in their negative health evaluations of themselves, and this was often mentioned by the mothers of girls too. Issues relating to diet and food were also a major cause of girls expressing guilt about themselves. Although body image and diet are very important to many teenage girls without diabetes, it is the particular emphasis placed on diet and food in diabetes that serves to disadvantage teenage girls with diabetes. In contrast, hardly any of the boys with diabetes mentioned food or diet.

The second area explored was that of exercise and sport. Again, the value of exercise in helping to control asthma and diabetes also served to disadvantage teenage girls who often took little exercise, and felt guilty about this. For many girls, this lack of exercise was seen as another important cause of their perceived unhealthiness. This study again supports the findings of Miller et al. (1993), who concluded that the social construction of femininities for young women does not include a great emphasis on organised exercise activity, with sporting participation amongst young women generally declining throughout the teenage years. In contrast, health was seen by both boys and their mothers to relate very much to the amount of sport boys played, and almost all of the boys in this study played a wide variety of sport. For those boys who were not keen on 'typical' male sports such as football, parents went to great lengths to find acceptable alternatives. Sport was seen to play an important part in the control of asthma and diabetes by both boys and their parents, but this was rarely the case with girls. The importance of the 'institution of sport' to the construction of masculinities noted by Connell (1983) is confirmed in this study, but his work is extended to include the impact this can have on chronic illness management. However, because of its importance in terms of masculine identities, the inability to participate in sport could lead to 'disparaged identities' for boys, illustrating the 'double-edged sword' notion described by Charmaz (1995).

10.1.3 Gendered Dependencies and Responsibilities

Mothers and health professionals have gendered views of young people's self-management abilities, being much more likely to see girls as independent and responsible, both in general and in relation to illness management, which supports the findings of Hill and Zimmerman (1995). The majority of girls interviewed appeared to take the initiative in terms of responsibility for self-management, often after little if any negotiation with mothers, and at
an earlier age than boys. It appeared that initially, girls often took responsibility to earn praise and gain status from pleasing others, but within a short time competent and 'invisible' self-management was routinely expected of girls. It seems that girls were responding to steroetypical expectations of feminine identities by being self-sacrificing, docile and virtuous (Coppock et al. 1995). As with Green and Hart's (1996) research on children and accidents, in this study girls were likely to present themselves as responsible, and this appears important in relation to the construction of feminine identities. Girls were very perceptive about not being reliant on others, and my research findings indicate that girls felt a loss of status, control and power in situations where they perceived themselves as dependent on others. This relates to the importance for feminine identities of being seen as responsible, and supports the work of Arber and Ginn (1991) who argue that women may acquire a more subordinate status as a result of dependency.

In contrast, although boys often presented themselves as responsible for self-management, they appeared unaware of the support and assistance they were given by their mothers. However, it should be noted that part of the skilled nature of this work of mothers lay in making the help given invisible, and this will be discussed in more detail in the following section. My research findings support and extend the work of Arber and Ginn (1991), who argue that in adults various forms of dependency are gendered and differentially evaluated by society. In this study, gendered forms of dependency which were differentially evaluated were also found to be operating for young people.

By interviewing both young people and their mothers, my research findings were able to throw some light on two pieces of research which appear to reach opposing conclusions in terms of the ability of girls to self-manage. If I had only interviewed mothers for this study, as did Hill and Zimmerman (1995), I would have concluded, as they did, that girls are more willing and able to exercise good judgement and self-management. Conversely, if I had only interviewed young people, as did Miller et al. (1993), I would have concluded, as they did, that teenage girls are more likely to have periods of 'non-compliance' than teenage boys. However, by interviewing both mothers and young people, the overall picture becomes clearer. My research findings show that just over half of the girls interviewed had intentionally had an often lengthy and sometimes potentially harmful period of non-adherence to therapy of which their mothers - and others - were usually unaware, although mothers and health professionals were sometimes aware of the 'poor' control which could result from this. As girls were considered to be autonomous in self-management by their mothers they were generally left to manage alone, which meant that the level of control girls chose to achieve was very much up to them. In contrast, boys were far more likely to be
advised and supported by their mothers. In the cases where boys were non-adherent to treatment, their mothers were very aware of the situation.

This links in with the meaning of 'guided' self-management, where power and control are maintained by health professionals through surveillance. Asthma and diabetes both carry high levels of personal responsibility in terms of self-management, and because discussions around health and illness take place within a moral framework, people are expected to show that they are doing their 'best' to control either condition. Girls were very aware that the ways in which they were adapting their regimes would not be seen as them doing their best to achieve control, so they consequently took steps to hide their actions. One of the results of this 'hidden' non-adherence was that many of the girls expressed feelings of guilt and shame which were not expressed by boys. My research findings both support and extend the research of Silverman (1987c), who observed outpatient consultations between doctors and adolescents with diabetes. He found that once the young person had been defined as an active decision-maker, she or he gained autonomy at the expense of being held morally responsible for her or his actions, with guilt being used as a subtle means of control. However Silverman's (1987c) work did not look at gender differences, and my research findings indicate that teenage girls are much more likely than boys to be defined as active decision-makers, and to feel guilty about their actions. However, these feelings of guilt did not appear to act as a subtle means of control in terms of leading to improved 'compliance', but served to make girls feel worse about themselves, which often exaggerated the problem.

This links in with Alderson's (1996) view of adolescence and transition as social constructs. Although girls were seen as active decision-makers, it is perhaps because they were also perceived as 'adolescents', and in 'transition' to adulthood, that guilt was used as a means of control. Although adults may also feel guilty for not keeping to their treatment regime, they generally have more power within consultations than young people do. This supports the work of Hockey and James (1993), who believe adults to have a power and decision-making responsibility which is denied to children. Alderson and Montgomery (1996) define autonomy as encompassing both the capacity and the opportunity to be autonomous, stating that the latter relies on having control over one's life. In this study, although girls were seen to have what Silverman (1987c) sees as the prerequisites of autonomy, namely independence and responsibility, they did not have full control over their lives, and according to the definition of Alderson and Montgomery, were not fully autonomous. Consequently, treatment which did not follow medical guidelines was hidden from health professionals and mothers, with resultant feelings of guilt.
10.2 Mothers' Roles in the Development of Gendered Identities

This section explores the important role of mothers in the development of gendered identities, including some of the consequences which can arise for mothers. Although this study set out to interview the 'key' parent in helping the young person with their disease and treatment, in almost every case this proved to be the mother. In line with much previous research, in most families it was just accepted by mothers, fathers and young people that caring for health, but particularly illness, was the responsibility of mothers (Chodorow 1978; Graham 1984; Anderson 1990).

There were many ways in which caring for a young person with an illness came to be seen as the mother's role, and these were all interrelated. In terms of the impact of their child's chronic illness on mothers' employment outside the home, employment prospects could be severely affected. In practical terms, this meant that mothers sometimes chose not to work, or they took part-time, often low paid jobs so that they were 'available' for their child. This also meant that mothers became more 'locked in' to caring responsibilities, whilst fathers tended to be 'locked out'.

Mothers had strongly gendered views in terms of the ability of their teenage children to self-manage. The mothers of girls were much more likely to talk in terms of them being independent and responsible, both in general and in relation to disease management. Boys were seen as in need of more care than girls, but unlike the research of Hill and Zimmerman (1995), this was not because the mothers of boys perceived their sons as sicker. In fact, the mothers of boys were much more likely to describe their sons as very healthy, and this often related to the amount of sport they played. In contrast, mothers were extremely unlikely to describe their daughters as very healthy, and seemed to judge the health of girls by different criteria, such as the fact that they were rarely ill, or did not have to take much time off school. Despite this, the mothers of girls did not invest more effort in their care-giving for daughters.

Care-giving appeared to be related to mothers' gendered views of dependencies, rather than to their assessment of the health of their child. The construction of social age appears to be gendered during late adolescence, with girls generally perceived as more mature and independent than boys of the same age, which supports Ginn and Arber's (1995) view that social ageing in adults is gendered, and extends their work into adolescence. This also relates to the notion of adolescence as a social and a gendered construct, in that boys were often seen by mothers as 'in transition' to independence, whereas girls were seen to be independent. This supports the work of Alderson (1996), who believes the concept of

The interaction of mothers' gendered views of dependency and the ways in which young people themselves managed chronic illness, combined to impact on the care which mothers gave to their sons or daughters. To enable boys with chronic illness to keep it apart from their personal and social identities, mothers performed a wide variety of supportive work at home, and appeared to subtly 'mute' the effects of illness and dependency. The research findings support the work of Mayall (1996), who argues that mothers are faced with difficult and contradictory tasks, which include preparing their sons for a gendered social world, whilst making it clear that such stereotypes do not necessarily hold at home. However, the results from this study indicate that teenage boys have already absorbed these stereotypes. In addition, in this study young people were seen to play an active role in constructing the work of mothers, and it is the interaction of the two perspectives that is important. In many ways, my research findings indicate that mothers are in fact responding to the agendas laid down by their daughters and sons. Charmaz (1991) draws attention to the fact that 'passing' can be risky, often requiring an 'alert assistant', and this term very accurately describes the role that the mothers of boys in this study often played. One of the skills involved in this role was in making the help given as invisible as possible, and this supports the work of DeVault (1991).

Mothers of sons were much more likely than the mothers of daughters to act as mediators, because boys tended to hide their illness in the 'public' sphere. Mothers acted on behalf of their sons, negotiating between 'private' and 'public' spheres, such as schools, and also within the home. This tended to be done in a 'conspiratorial' way so that boys did not have to be involved, and could therefore maintain a 'normal' self-presentation. Mediating was discussed in relation to the work of Ribbens (1994), who believes that this exercise of power may be seen as indicative of caring, drawing on Rich's suggestion that women's use of power may be found not in power over others, but in 'transforming power' (1977: 99).

The mothers in this study played a part in the development of gendered roles and dependencies. In some cases, the mothers of boys expressed hope that their role would eventually be handed on to another woman. In contrast, mothers of girls expressed hopes that their daughters would marry someone who would look after them if they were ill, rather than someone who would help with the maintenance of everyday health. Mothers of girls also had expectations of them in terms of housework, even though this might be detrimental to their health. In addition, the mothers of daughters seemed more likely than the mothers of
sons to describe complaints of symptoms as 'acting up', which supports the work of Blaxter (1982). My research findings suggest that mothers were preparing girls for their future roles as carers within households, whilst mothers of sons hoped that boys would be cared for by a future partner, who would take over the role of the mother.

10.2.1 The Autonomy/Responsibility Conflict

In this study the care by mothers for this age group was complicated by the autonomy/responsibility conflict highlighted by Silverman (1987b). Silverman (1987b) describes the difficult situation that parents of adolescents with diabetes can be placed in, in that they are expected to balance the conflicting norms of acting responsibly, with respecting the young person's autonomy and ability to self-manage. My study extends the work of Silverman (1987b) in two ways. Firstly, it found that the conflict affects mothers in particular, as they are the parent most likely to be seen as responsible for care. Secondly, my research findings indicate that the differential effects of the conflict relate to the gender of the young person. This study found that mothers of girls were more likely to be blamed by health professionals for their daughters' poor control, particularly in relation to diabetes. This was despite the fact that girls were often seen as autonomous in self-management, and this had been encouraged by health professionals. The influence of psychological discourse on health professionals was also noted in relation to the emphasis they placed on dysfunctional mothers, and poor mother-child relationships.

The mothers of sons were placed in an equally difficult position, as they were accused of overprotecting, or 'mollycoddling' their sons by health professionals and other family members, particularly fathers. 'Mollycoddling' seems to strike at the heart of the social construction of masculinities, threatening the successful transition of boys into 'proper men' (Prout 1986). It was argued that this was the reason that it proved such a source of anxiety for mothers, and it was also often the reason that fathers became involved. This supports and extends the work of Duncombe and Marsden (1995), who found that men were likely to see women's emotional work with children as unnecessary and debilitating 'fussing'. My research indicates that in adolescence it is far more likely to be the fathers of sons, rather than the fathers of daughters, who make these accusations. When attempting not to 'mollycoddle' sons, mothers could also be blamed for not protecting their sons enough, and this illustrates the 'no-win' situation they could be placed in. The sensitive nature of this was illustrated by what I called 'developmental activity', by which mothers encouraged independence in boys. Mothers carefully planned out each step, fearful that if they 'pushed' too hard, it might be counterproductive. Part of the skill and ultimate success of this activity lay in making it invisible. Although superficially, this work fits into Mason's (1996)
concept of sentient activity in that it is a time consuming, draining and often solitary 'thinking and feeling' activity, it seems that this is a specific type of activity and for this reason, it was called 'developmental activity'.

In general, Mason's (1996) conceptualisation of caring as sentient activity and active sensibility was very useful in helping to describe and uncover the work that the mothers in this study performed. The concept of sentient activity was particularly useful in drawing attention to the skilled nature of the often gruelling but usually invisible work performed by mothers, which would otherwise be described as 'worrying', or subsumed under the concept of emotional labour. The concept of active sensibility allowed a more sensitive analysis of the ways in which caring, gender, and family relations intersect relationally to produce differences in caring. Much of the work on caring relates to women, and the concept of active sensibility allows the caring role of men to be recognised. In addition, the concept of active sensibility acknowledges the active roles played by both young people and mothers when negotiating care. However, the concepts were not wholly appropriate for this study, and this led to the introduction of a new term, 'developmental activity', to describe a specific activity which took up a large amount of the time and energy of mothers, particularly those who had sons with a chronic illness.

10.2.2 The Effects of Ultimate Responsibility on Mothers

The effects on mothers of performing these activities was extensive. Mothers of both girls and boys were accused of 'nagging', which Silverman (1987b) also found in his research on parents and teenagers with diabetes, stating that nagging can be seen as the 'other side of the coin' to responsibility. Silverman (1987b) talks about nagging in ungendered ways, but my research findings indicate that only mothers were seen to 'nag'. It was argued that nagging was one way in which mothers manifested their feelings of responsibility for their child. Nagging was discussed in relation to Maguire's (1992) work, in which she relates nagging to the power which operates by controlling women's perceptions of themselves. She believes nagging to be an example of language being used against women.

In this study mothers nagged for two main reasons. Firstly, it related to the concerns felt by mothers for the future health of their child, a concern which they felt young people did not have. This future orientation could place mothers in a position of conflict with health professionals. Mothers sometimes felt that health professionals concentrated on making the young person's life more tolerable in the present, which from the viewpoint of mothers made 'good' control harder to enforce. This could lead to mothers being blamed by health professionals for nagging unnecessarily, and supports the work of Goldner, who states that...
even though health professionals tell mothers not to be so helpful, they rely on mothers' 'ironclad sense of responsibility to get things done' (1985:41). This highlights very clearly the difficult position mothers are placed in. Secondly, nagging related to the perceived dangers mothers felt the 'public' world might hold for their teenage children. Much of this related to the 'just in case' factor which did not usually occur, and consequently mothers were made to feel that they were nagging unnecessarily. However, if 'just in case' did happen, and mothers had not taken precautions, mothers could be blamed, and blamed themselves for not being responsible.

These feelings of responsibility support previous research on mothers (Brannen et al. 1994; Hughes et al. 1980). In the interviews, this responsibility also led to 'displays of competence' which I called 'justification talk', by which mothers appeared anxious to show that they had done everything possible to help their child. This supports the findings of Anderson and Elfert (1989), who noted the serious consequences not displaying competence has for mothers, both within the family, and in interactions with health professionals and others. They place this in the context of 'the ideology of competence' within which, they claim, the care of mothers is judged by others, and by themselves.

However, there is no indication in the work of Anderson and Elfert (1989) that displays of competence might relate to the gender of the child or young person. In my study the care of mothers and displays of competence were both seen to relate to the gender of the young person. My research findings also indicate that mothers' lives were particularly likely to be adversely affected if sons had given up hope of gaining control over their illness. This was partly because mothers had knowledge of the situation, as they were much more likely to be involved with the care of sons, whereas daughters in the same situation tended to be more secretive about their problems. This supports the findings of Charmaz (1995), who noted that some men used the uncertainty of chronic illness to keep hold of power and privilege within the home, with wives placed in the position of cajoling them in terms of treatment. However, it may relate to gendered meanings of 'the ideology of competence', in that the competent mothering of boys is somehow seen as more important than the competent mothering of girls. As Flax (1978) states, mothers may 'value' sons more, which reflects the higher social esteem men generally have. It may also be that as mothers are more likely to be involved in the care of their sons, they feel that any problem with care reflects directly on their competence. In contrast, because of the expectations on girls to be more independent and responsible, any problems reflect on the girls themselves.
10.3 Health Policy Implications

In qualitative research, issues relating to the representativeness of the sample and the generalisability of the findings are not paramount, the concerns being to establish theoretical links within each case, and to replicate findings in other sets of conditions (Brannen 1992). Subsequent research can focus on assessing the validity of this research in other settings, but from my research findings I feel that it is possible to make some suggestions for health policy. In doing this I am aware of the argument of Silverman, who states: 'change the constraints of the setting and people will behave differently' (1993: 210). It is easy to be critical of health professionals who are often working under difficult circumstances. However, the majority of these recommendations are more about changes of attitude, and do not involve major financial implications or complex reorganisations.

In their ways of managing chronic illness, young people should be seen as acting rationally within the confines of their gendered identities, and health professionals need to recognise the part they play in reinforcing gendered management styles. For example, health professionals should be aware of the pressures girls are placed under to act responsibly, and to take over self-management at a young age. Health professionals need to be cautious when giving praise to girls for being responsible, and it should be emphasised to girls that they may want - or, it is expected that they will want - to take 'time out' from self-management. Partly because of the pressure they feel under, girls are more likely to 'hide' non adherence for various reasons, even though their mothers - and health professionals - may think that girls are completely adherent to treatment. This can sometimes lead to girls being labelled as having 'brittle' diabetes or 'brittle' asthma, when in reality the cause of the instability can be a lack of adherence to treatment. Girls are also likely to have feelings of guilt and self-blame as a consequence of this. In relation to girls with diabetes, issues relating to exercise, but particularly to diet and food have a markedly gendered impact, leading to frequent feelings of guilt and blame amongst girls. Health professionals should be sensitive to these feelings and their causes, and a reduction in the emphasis on diet, weight, and exercise may help girls.

In terms of the self-regulation of treatment, health professionals need to recognise that this is often a positive action, with girls adapting regimes to suit their daily lives. It should be discussed in a non-judgemental way, with the recognition that young people are the experts in living with their chronic illness. Girls are more likely than boys to want to talk about their feelings in relation to having a chronic illness, and may welcome the routine offer of speaking to a counsellor, or someone not directly related to their treatment. This service should be seen as part of routine care, and not as something to be offered when problems
arise. It should also be noted that the greater adaptability that girls show towards chronic illness may have detrimental effects. Girls may lower their expectations for themselves, and this can be supported by others such as teachers. In relation to diabetes, the greater adaptability of girls can also result in poorer control of blood glucose levels.

It should be recognised that teenage boys also manage illness in gendered ways, often with the aim of making the illness publicly 'invisible'. In terms of asthma, boys are much more likely to want to treat it as an acute episodic event rather than as an illness requiring daily preventive treatment. Where this situation arises, perhaps a 'damage limitation' strategy would be more useful than trying to persuade the use of preventive treatment. The recognition of danger signals in relation to their own condition should be discussed with boys, and they should know when to seek emergency help. The importance of sport to many boys could be used as a lever to encourage the use of preventer inhalers. However, it should also be noted that mothers can be influential in dissuading their sons from taking regular preventive treatment, because of their concerns about steroids.

In relation to teenage boys with diabetes, it may be very difficult to persuade them to use a more flexible regime of four injections per day, as they are unlikely to be willing to perform injections at school. This should be seen as a rational decision taken within the confines of the meanings of illness to masculine identities. Because of the gendered meanings that showing particular emotions has, boys may decline the offer of talking to a counsellor, although a service should again be offered routinely. The type of service offered may need to be sensitively adapted to the specific needs of boys, but it should be recognised that mothers are often playing a major role in helping boys manage their diabetes, both emotionally and practically.

Some of these gendered behaviours may seem unhelpful to disease management, but it appears that masculine ways of managing chronic disease can be advantageous. In general, boys were less likely to let their disease impact on their achievements. However, health professionals should be aware of the problems that can arise when boys feel that they cannot control their condition, or its impact on their lives. In these circumstances boys may react angrily and refuse to attend clinics, thus disappearing from the 'system'. The results from my study indicate that teenage boys are more likely to move between the two extremes of managing either very well, or very poorly. As mothers are likely to be very involved in helping boys manage, they are usually the first person to detect problems arising. In this study mothers reported having alerted health professionals to difficulties, but being made to feel that they were 'fussing' unnecessarily, with no help being offered. It seems that any such warnings from mothers should be taken very seriously, and mothers should be
involved in deciding what type of help would be most appropriate. The stress and concern felt by mothers in these circumstances cannot be underestimated, and they will also need support and reassurance.

Health professionals should recognise that they often help place mothers in a very difficult position. Mothers are expected to encourage autonomy in their teenage children, but are still held responsible by health professionals if things go wrong. They are also placed in what is frequently a 'no-win' situation, in that they can be blamed for 'mollycoddling', and for 'nagging'. The part that mothers play in helping the young person manage should be recognised and supported, but the work of mothers is all too frequently 'invisible', only becoming visible when problems arise. Health professionals need to understand the pressure mothers are under from the 'ideology of competence' (Anderson and Elfert 1989), particularly in relation to having a child with a chronic illness. This can lead to feelings of guilt which health professionals can both engender and confirm. Mothers should be offered counselling as part of a health care package, and again, this should be seen as separate from those involved with the treatment of their child's asthma or diabetes.

In a more general sense, the whole issue of 'guided' self-management is seen as unproblematic by health professionals, with little understanding of the ways in which power and control of the consultation are still held by them in this situation. This is particularly the case when they are dealing with young people who are seen as 'in transition' between childhood and adulthood.

This study did not set out to assess the benefits of the ways in which different clinics were organised. However, it appeared that in terms of diabetes, the outpatient clinic of one particular hospital proved more acceptable to young people and their parents. Some of its key features included:

- privacy for consultations - this may seem a minimal requirement, but in one hospital young people and mothers reported embarrassing consultations taking place with the nurse in the Waiting Area, in full hearing of everyone else.
- short waiting times, with a television to watch whilst they were waiting. Being kept waiting for clinic appointments was one of the factors that caused most annoyance, and discouraged young people from attending clinics. They were often missing important school lessons, and in addition, young people found it depressing to sit and contemplate their condition.
- the attitude of all staff, which was that young people were treated as adults capable of making decisions about their treatment. There was a less punative attitude in this clinic, with issues such as 'poor control' being treated more sympathetically. Staff were supportive.
and accepted that diabetes could be difficult to live with, unlike other clinics where difficulties were minimised, with blame apportioned to the young person.

- parents were involved and welcomed in the clinic, which meant that they had confidence in the staff. There was a much clearer understanding about who was responsible for what in terms of illness management, and this was discussed in a non judgmental way.
- above all, young people treated in this clinic seemed to feel more in control, because their views - and they themselves - were treated with respect.

In conclusion, my research findings indicate that in the late 1990s, gendered notions of caring, dependence, and responsibility are still very powerful and pervasive in both the private and public worlds of young people and their parents. The gendered management of chronic illness is just one of the ways in which this is manifested. Focusing on two illnesses has enabled this study to show that what may superficially appear to be very different ways of managing illness serve the same purpose, that of maintaining gendered identities. The findings of my study indicate it likely that because of the ways in which femininities and masculinities are culturally endorsed, the reproduction of similar gender divisions between women and men will continue in the foreseeable future.
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Appendix A

Home telephone number: 0181 898 6728

Dear ........,

My name is Clare Williams and I am a nurse researcher at Surrey University, funded by the Department of Health. I have been given your name by Dr ......, consultant at ..... Hospital, who thought that you might consider taking part in my research project.

I am doing research to find out how asthma/diabetes affects the lives of young people and their parents, and hope that in time this research will lead to improvements in care. I would like to talk to both you /and your mother /and your daughter/son separately to hear your views. With your agreement the interview will be taped so that I have an accurate record of what you have said. Each interview will probably last for about one hour and the time will be arranged to suit you. I can come to your home, or we can arrange to meet somewhere else if that is more convenient for you. Everything that you tell me will be totally confidential and will not be discussed with anyone else - that includes doctors and other members of your family.

I will ring you in a few days to talk about the research, and can answer any questions you may have - alternatively, you can ring me at home. Your decision about whether or not to take part in this project should be totally your choice, and your decision will not in any way affect your/your daughter's/son's medical care. The Local Research Ethics Committee has approved this letter of information. Thank you for considering this request.

Yours sincerely,

Clare Williams

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Surrey GU2 5XH
England

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Appendix B

CONSENT FORM

I have agreed to be interviewed by Clare Williams, a nurse researcher at Surrey University. I realise that the interview is entirely voluntary, that I can refuse to answer any question, and that I can stop the interview at any time. I understand that everything I say will be totally confidential and will not be discussed with anyone else - that includes doctors and other members of my family. I also understand that any reports of this study will not be able to identify me in any way. I give permission for the conversation to be taped.

Respondent’s signature

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Interviewer’s signature

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Date:
Appendix C

Parent's Interview Guide

1. Medical History - how it all started

• can you tell me about the time when your daughter/son was diagnosed as having asthma/diabetes?
• how did it affect your daughter/son?
• how did you feel at that time?
• what about the rest of the family?
• was there any tendency to overprotect your daughter/son at that time?
• who supported you at that time?

2. Since then

• have you had any thoughts on what the cause of the illness was - or why it came on when it did?
• have there been any particular problems, for example, has your child had to go into hospital?
• how well would you say that your daughter/son has adjusted to having diabetes/asthma - could you describe how this process took place?

• could you describe any extra work/caring you do in relation to your daughter's/son's diabetes/asthma?

3. Treatment

• does your daughter/son manage her/his own treatment, or do you help?
• would you say s/he is quite good as far as managing treatment goes - confident?
• when did s/he start managing on own - did you think that was too early, late or about right?
• when do you think that your daughter/son should go and see the doctor on her/his own - make medical decisions on own?
• how would you rate your child's independence?
• what part do you think that you as a mother/father should play in keeping your daughter/son healthy?
• do you think that your daughter/son feels in control of the asthma/diabetes, or do you think it's the other way round?
• has your daughter/son ever been through a period when s/he wouldn't take the prescribed treatment?
• can you think of anything that caused that behaviour?
• what was your reaction - did it cause any arguments?
• where do you get most information from in relation to diabetes/asthma?
• how do you get on with the health professionals involved in your daughter's/son's diabetes/asthma?
4. Stigma

- has your daughter/son ever felt different because of asthma/diabetes?
- has this affected her/him - in what ways?
- how are the teachers at school? Does having diabetes/asthma affect anything s/he does at school?
- does anyone treat her/him differently because of asthma/diabetes?
- has it made any difference to the way that you treat him/her?
- is there any situation when she/he would try and hide the fact that s/he has asthma/diabetes?
- has any of this changed over time?

5. Social Life

- does having asthma/diabetes stop your daughter/son doing anything?
- Is there anything that you think s/he shouldn't do - do you disagree about this - if so, how do you come to an agreement?

6. Gender

- is there anything about living with asthma/diabetes that you think is easier/harder for your daughter/son because s/he is a girl/boy?
- do you think that in general boys or girls are better at looking after their own health - or no difference?
- do you expect more from your daughter/son because s/he's a girl/boy?

7. Control

- do you think that good health is down to luck, or do you think that each person has control over her or his own body?
- what factors do you think help a person to be healthy?
- what does being healthy mean to you?
- how would you rate your daughter/s/son's health?
- do you worry about your daughter/s/son's health?

8. Future

- do you see asthma/diabetes affecting your daughter/s/son's future at all?
- do you know whether your daughter/son has any worries about the future?

9. General

- how do see being a young person today?
- do you consider your daughter/son to be an adult - what does being an adult mean to you?
- what do you see as being the parent's role in the 90s?
- how would you describe your relationship with your daughter/son?
- if you disagree over something how does it get sorted out?
• what effect has asthma/diabetes had on the other family members?
• has having a child with diabetes/asthma stopped you from doing anything that you wanted to do?
• what would be the one thing that would make - or would have made - caring for your daughter/son easier?
• is there anything in relation to being the mother/father of a young person with diabetes/asthma that I haven’t asked you about, that you would like to add?
Appendix D

Young Person's Interview Guide

1. Medical History - how it all started

- symptoms
- experience of hospital
- starting treatment - how did you feel?
- what were your thoughts around that time?
- who helped most at the beginning?
- what did your friends say?
- how did your family react?

2. Since then -

- any particular problems, for example have you had to go back into hospital?
- any thoughts on what the cause of your illness was - or why it came on when it did?

3. Treatment

- describe treatment now, including blood sugar monitoring, peak flows etc.
- do you monitor your own blood sugars / peak flows as often as you have been asked to?
- do you change your insulin doses / asthma treatment around on your own?
- do you feel in control of your diabetes/asthma, or do you think that it controls you?
- do you manage your treatment on your own, or do your parents/friends help/remind you about it - which parent?
- what part do you think your mother / father should play in keeping you healthy?
- how do you get on with the medical/nursing staff concerned with your treatment?
- how often do you go to see them - what happens when you see them - are the clinics helpful - what do they expect you to do in terms of treatment - right level of responsibility?
- who decides if you need to go and see the doctor when you’re ill - do you decide on your own, with your parent/s, or do they decide for you?
- have you ever been through a period when you didn’t take your treatment?
- can you remember what brought that on?
- what was the reaction of your mother and your father when that happened?
- did it cause arguments?
- where do you get information about diabetes/asthma from?
- do you ever ask for help with your treatment - how do you feel about doing this?
4. **Stigma**

- have you ever felt different because of your asthma /diabetes?
- has this affected you - in what ways?
- how are the teachers at school? Does having diabetes / asthma affect anything you do at school?
- do you think that anyone treats you any differently because of your asthma/diabetes?
- how has this affected you?
- is there any situation when you would try and hide the fact that you have asthma / diabetes?
- do you discuss asthma/diabetes with your friends?
- is there anything about your life that would be different if you didn't have diabetes/asthma?
- what does having diabetes/asthma mean to you?

5. **Social Life**

- do you avoid any situations because of asthma/diabetes?
- does it stop you from doing anything?
- do your parents ever try and stop you from doing something because of your asthma/diabetes?
- do you ever plan things around asthma/diabetes?
- how about smoking / drinking alcohol - does that affect your asthma / diabetes?
- does it affect any situation with your boyfriend/girlfriend?

6. **Gender**

- is there anything about living with asthma /diabetes that is made harder / easier because you’re a girl /boy?
- do you think that your parents expect more / less from you because you’re a girl/boy?

7. **Control of Health**

- do you think that good health is down to luck, or do you think that each person has control over her/his body?
- what does being healthy mean to you?
- what part does asthma/diabetes play in your life?
- do you think of yourself as a healthy person?
- what are you thinking about when you describe yourself in that way?
- what part do other people play in keeping you healthy?
8. Future

- how do you see your future?
- do you have any worries about the future?
- do you see asthma/diabetes affecting you in any way in the future?

9. General

- how do you see being a young person today?
- when do you think that you moved from being a child to being a teenager/adult?
- has being a teenager brought any problems with it - any advantages?
- do you think that having asthma/diabetes has made you grow up faster, slower, the same as your friends?
- do you consider yourself to be an adult now?
- how would you describe your relationship with your mother - father?
- which parent are you closest to?
- who would you turn to if you were worried about something?
- what is the worst thing about having asthma / diabetes for you? Has anything positive come out of having asthma/diabetes?
- what would be the one thing that would make - or would have made - managing your diabetes/asthma easier?
- is there anything else that you would like to say that I haven't asked you?