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A Personal Construct Theory approach to addressing adherence in an adolescent asthmatic population

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ABSTRACT

This study is an exploratory investigation into understanding adherence behaviour in a random sample of 13 asthmatic adolescents selected from a General Practice population. Personal Construct Theory is used as a theoretical and methodological framework within which to assess the meaning of having asthma and taking medication to each participant. Asthma and adherence perceptions are also obtained in a semi-structured interview. Measures of subjective asthma status are obtained using a global severity rating scale and the Paediatric Asthma Quality of Life Questionnaire. Subjective measures of adherence are also obtained from the participant, their parent and their health-care provider.

A qualitative analysis of the results reveals that, for the majority of the sample, self-construal of adherence is consistent with self-construal of asthma. A content analysis of elicited constructs reveals a category of themes, which show direct parallels with models of health behaviour change and adolescent development. It is proposed that these results provide the basis for the development of a model of adherence in asthmatic adolescents.

The validity of the grid methodology is assessed through feedback of the results to the participants and comparison of data sources. It is concluded that the grid is a valid tool for addressing perceptions of asthma and adherence. Reliability of the methodology is not addressed.

Implications for the use of the methodology within a clinical setting and recommendations for further research are discussed.

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CHAPTER 1

Introduction

1.1 Asthma: Illness Parameters

Asthma is one of the most prevalent and disabling chronic health problems affecting people across the life span. A recent review of asthma prevalence studies concludes a trend of increasing incidence world wide, and particularly within Western (urbanized) as opposed to developing countries (Beasley et al., 2000).
In the UK it is estimated to affect between 10 and 15% of the population, and is the third greatest cause of hospital admissions (Bennett et al., 1998). Within the paediatric population, it is estimated that 4-6% of children in the UK have asthma that is sufficiently severe to require medical supervision (Dept. of Health, 1995). Despite improvements in asthma care it continues to be a leading cause of school absence, hospital admission, and is a significant cause of morbidity in children (Budetti & Wiess, 1993). The economic implication of asthma is considerable. In the UK in 1993, 11% of the total net costs of prescriptions were spent on asthma drugs. In the same year 103,000 hospital admissions were for the condition (Burr, 1993).

Asthma is characterised by shortness of breath accompanied by wheezing, coughing, dyspnea and exhaustion, which is the result of the narrowing of the bronchial airways by muscle spasm, inflammation, mucosal swelling or viscid secretion. An asthmatic episode may last between minutes and hours, or even days. In the most severe circumstances, asthma may lead to extreme respiratory distress and arterial hypoxaemia, which unless treated can lead to death.

The medical model of asthma care involves a complex set of strategies and advocates the use of inhaled preventative or prophylactic medication (British Thoratic Society, 1997). The emphasis has shifted from symptom relief to the prevention of asthma. The rational for the adoption of preventative regimens arises out of concerns that reversible airflow obstruction may be a precursor of progressive and irreversible decline in lung function (Carpenter et al., 1989). Several consensus reports now define asthma in this fashion (Global Initiative for Asthma, 1995; National Asthma Education and Prevention program, 1997). Although there is little evidence to substantiate this view (Oswald et al., 1997; Gerristen et al., 1989), it has prompted an aggressive treatment culture, with use of prophylactic medications early on in childhood (Warner et al., 2000). The relieving effects of B2-agonists are immediate and readily noticeable; however, the anti-inflammatory effects of corticosteroids are delayed and less easily perceived. Therefore the use of preventative medication is necessary, even when the patient is symptom free.

1.2 Developmental Aspects of Health and Illness

It is argued that health and illness are directly related to developmental processes, with morbidity and mortality showing distinct patterns across the life span (Penny et al., 1994). Stage theories of development propose that development occurs in ordered sequences, with patterns of development common to groups of individuals. The impact of a health problem (both in its meaning to the individual, and the ability to cope with it) varies according to the stage of life in which it is experienced, and certain periods may be "at-risk" for certain types of adjustment problem (Band & Weisz, 1990). The behaviours that are adopted to enable adjustment to an illness at a particular life stage have considerable implications for health in future stages. The "developmental

course of the disease" is also an important variable to consider as it works alongside developmental factors and impacts upon adjustment. While some diseases become more severe with increasing duration, others are marked by periods of crisis followed by relative quiescence.

The current thesis is concerned with the experiences of chronic illness during adolescence. Psychosocial aspects of adolescent development are discussed with reference to the impact of a chronic illness such as asthma.

1.3 Adolescence

There is some disagreement about the definition of adolescence. Pubertal development is often considered the clearest demarcation of the transition from childhood to adolescence (Buchanan et al., 1992). Although the age at which this occurs varies considerably between individuals, the age of 10 years is frequently used (World Health Organisation; WHO, 1980) as it includes the onset of puberty in both sexes and most individuals. The upper age limit is less well defined. In Western cultures it is typically identified by the development of the ability to live independently of parents with commencement of employment, and the age of 19 years is commonly used (Nutbeam & Booth, 1994). This upper age limit, however, is essentially culturally bound. For example in more traditional cultures, adulthood may be marked out at a much earlier age.

1.3a Adolescence: Physiological Development

Puberty is marked by endocrinological changes that result in rapid skeletal and muscular growth, the appearance of secondary sexual characteristics and the attainment of reproductive maturity in both males and females. Puberty does not occur in isolation, however, it interacts with psychosocial variables and together these influence the development of the individual adolescent.

1.3b Adolescence: Cognitive Development

Adolescence is characterised by significant changes in cognitive abilities. According to Piaget's theory of cognitive-development (Piaget, 1972), adolescence is accompanied by the development of formal-operational thought, the ability to think abstractly and engage in hypothetical-deductive reasoning or logical thought. Piaget's theory emphasises universal and consistent patterns in cognitive development; however, numerous studies illustrate considerable variation in the cognitive abilities of the adolescent. A significant criticism of the theory demonstrates that not all late adolescents or adults use formal operational thought in the way described by Piaget (Keating, 1980). Therefore, it should not be assumed that all adolescents have the ability to think in formal-operational ways.

Cognitive development influences patterns of socialisation during adolescence. 'Egocentrism' refers to the heightened self-consciousness of adolescents, which is reflected in the belief that others are as interested in them as they are themselves, and their sense of uniqueness (Elkind, 1967). The belief in personal uniqueness colours adolescents' approach to life, and results in a conviction of personal invulnerability and a preparedness to take much greater risks. These cognitive changes are considered one

factor accounting for the excessive 'risk-taking' behaviour (such as the use of illicit drugs, unprotected sexual intercourse), which is commonly associated with adolescence.

1.3c Adolescence: Social Development

The social changes characterised in adolescence are underpinned by an increased 'autonomy' or independence. Greenberger (1984) proposes that "self-reliance" is the basic disposition that underlies autonomy, *"the absence of excessive dependence on others, a sense of control or agency over one's life and an action orientation or sense of initiative"*. Anna Freud (1958) viewed adolescence as a period of 'detachment' from parental ties, a process leading to emotional adjustment, healthy independence and later attachment to extra familial objects. However, recent research does not support this process of detachment. For example, the majority of adolescents feel close and respect their parents and most continue to be influenced by their parents during adolescence (Frank et al., 1990). Further, research suggests that familial environments which promote a sense of connection as well as individuation impact positively on ego development, self-esteem and identity formation (Hause & Powers, 1984). Therefore becoming autonomous and maintaining interdependence and attachments with parents are complementary and not mutually exclusive processes.

Adolescence is also characterised as a time of affiliation and conformity to a peer group. It is hypothesised that peer identification has functional implications for social development. Sullivan (1953) proposed that peer interactions had implications for later life in relation 'learning about relationships' (intimacy) and moral development.

1.3d Adolescence: Identity Development

Identity development is not inclusive to adolescence. It starts with the appearance of attachment and a sense of self within the first months of life. However, the physical, cognitive, social and emotional changes over this period are considered to have significant implications for the formation of an adult identity. As stated by Erickson (1959) in his developmental stage theory, the task of adolescence is one of "identity formation" versus "role confusion". Erickson suggested that fidelity is the essence of identity where the task of the adolescent is to become committed to an ideological worldview, a vocation and a sexual identity. Attitudes and beliefs, motivations and personal control, self-image and self-esteem are subject to considerable development over this period. Therefore, adolescence is a very important stage for the development of a "sense of who one is" which is carried through into adulthood.

1.4 Adolescence: The Impact of Chronic Illness

The experience of chronic illness during adolescence is likely to exaggerate further the challenges of the adolescent period. Adolescents with a chronic illness are constantly struggling with independence as they remain tied to their families for physical, financial and emotional support in relation to the management of their illness. This period of time is also stressful for the parent, who may be reluctant to "let go" of the adolescent following concerns about their ability to cope on their own. The adolescent is likely to resent this dependence.

Chronic illness over this life stage often aggravates concerns about physical appearance, especially in conditions or treatments which are associated with delayed physical maturity (Varni et al., 1993). Ill health and treatment requirements often place

constraints on the opportunities for individuals to mix with their peers, and this may evoke feelings of being different and lead to social withdrawal (Kyngas et al., 2000). There are also vocational implications as schooling may be disrupted, resulting in scholastic underachievement and reduced opportunities for employment.

Cognitive developments during adolescence enable the individual to comprehend the nature and implications of the disease from a more scientific or medical perspective, and therefore they acquire a more thorough understanding. However, this is accompanied by a greater insight into the consequences and complications of the disease and an awareness of personal vulnerability (Allen et al., 1984). Therefore, the adolescent may have a greater understanding, but be less able to cope with the disease.

Essentially, all of these factors may impact upon an individual's emerging sense of competence and self-esteem. Low self-esteem and social dependence are more common in adolescents with chronic diseases compared to healthy peers (Regan et al., 1993; Hause et al., 1993). In addition, with the recognition of the importance of these factors on a developing identity, the experiences of chronic illness may lead to dependent and life-long sick self-perception.

1.5 Psychosocial and Emotional Correlates of Asthma in a Paediatric Population

A focus of the research within the field of asthma has been into documenting the impact of asthma on psychosocial and emotional functioning. Emotional disturbance is not the inevitable consequence of chronic illness in childhood/adolescence, and most individuals cope remarkably well. A minority, however, do experience adjustment problems. Within a given disease, children and adolescents who are in poorer health

often exhibit more adjustment problems. For example, several of the large epidemiological surveys have reported increased rates of behavioural problems in children with severe asthma but not in children with mild/moderate asthma (Bussing et al., 1995; Graham et al., 1967). Other groups have found higher rates of psychological disturbance in children hospitalised for difficult to control asthma (Mrazek et al., 1987; Wamboldt et al., 1996). Panides and Ziller (1981) found that children who required steroid treatment had greater problems with self-esteem than those with mild asthma. Kashani et al. (1988), however, used both parental reports of child problems as well as structured psychiatric interviews but did not find a relationship between asthma severity and rates of psychopathology in children.

Some of these disparities can be explained by variability in the definition of "severity" throughout the literature. For example, in some cases severity has been measured through symptom presentation, in others through the effect asthma has had on functional status. In a review of the literature, Bender and Klinnert (1998) have suggested that asthma functional morbidity is associated with psychological problems. This is supported by studies that have demonstrated a significant relationship between degree of impairment with activities of daily living and psychosocial adjustment (Orr et al., 1984).

Causal relationships between variables have typically been difficult to assess. For example, research has identified that psychological factors can influence and indeed be influenced by asthma. The term "psychosomatic asthma" has been utilised in studies that have found that variables such as emotion, suggestion and stress can influence symptomatology. For example, psychiatric symptoms, particularly anxiety and depression, have been shown to be risk factors of an increase in asthma morbidity and

mortality (Wamboldt et al., 1996; Strunk et al., 1985). Conversely, the very nature of asthma may work to impact upon psychological factors. For example feelings of panic and fear, associated with an inability to breath normally, are often experienced during acute episodes.

A young person's experience of a chronic illness such as asthma is not detached or isolated from the system within which they live, thus the family system plays a significant role. Asthma is often a cause of considerable stress within the family. Effective management may require the adjustment of family activities (such as avoiding triggers or being prepared for the possibility of emergency care) and impact upon dynamic relationships (e.g. resulting in the compromise of spouse interactions - Weinstein et al., 1997). Gustafson et al. (1994), for example, in a prospective study of the relationship between family stress and development of asthma, found that dysfunctional family interaction seemed to be a result of the experience of asthma within the family.

Conversely, a number of studies have indicated that familial factors impact upon asthma. For example, in a sample of adolescents with severe, chronic asthma, higher levels of parental criticism have been found to impact upon asthma severity (Wamboldt et al., 1995). Those adolescents whose parents were rated as high in criticism showed greater improvement in asthma severity and reduction in steroid medication dose on admission into hospital. In addition, parental criticism was correlated with poorer compliance on admission. Minuchin et al. (1975) used the term "psychosomatic family" to describe the mechanisms by which an illness can be maintained by the structure of the family. Enmeshment or over-involvement between family members, rigidity, over-

protectiveness and lack of conflict resolution were identified as characteristics of the family that fostered and maintained asthma.

1.6: Quality of Life (QOL)

The concept of "quality of life" has arisen from the recognition that patient's and their families have a unique perspective on how diseases affect their lives. Traditional medical outcome measures, such as the assessment of signs and symptoms identify parameters associated with the disease, but say little about the functional or psychosocial consequences. For example, studies in adults with asthma have consistently shown modest correlations between conventional clinical outcomes and how patients feel and function in day-to-day activities (Juniper et al., 1993; Rowe & Oxman, 1993).

QOL measures can be subdivided into overall QOL and health-related QOL (HRQOL) subtypes. Overall QOL refers to the way *"patients perceive and react to their health status and to other, non-medical aspects of their lives"* (Gill & Feinstein, 1994 pp.619). HRQOL refers to *"the subjective and objective impact of dysfunction associated with an illness or injury, medical treatment, and health care policy"* (Speith & Harris, 1996 pp. 176). A number of instruments have been developed to assess generic or disease-specific measure of HRQOL. Generic measures are intended for a variety of acute or chronic health problems, whereas disease-specific measures are restricted to particular diagnoses or patient subgroups (Aaronson, 1989), and have greater clinical sensitivity and utility as they capture unique physical and psychosocial sequelae of specific diseases. A number of instruments have been developed for assessment of QOL in an asthmatic paediatric population, for example the Childhood

Asthma Questionnaires (Christie et al., 1993), and the Paediatric Asthma Quality of Life Questionnaire (Juniper et al., 1996).

There is agreement within the literature that QOL is a multidimensional construct consisting of the following core domains; physical symptoms; functional status (ability to perform age-appropriate daily activities); psychological functioning (affective states, self-esteem); and social functioning (number, type and quality of social contacts/relationships) (Aaronson, 1989; Speith & Harris, 1996). Other domains have been identified (such as cognitive functioning and school-related performance) and QOL measures vary in terms of the domains which are assessed. Although no consensus exists on the criteria for a good quality of life instrument, it is agreed that it should be multidimensional, subjective, easy to use, reliable, sensitive and valid (Apajasalo et al., 1996; Juniper et al., 1996).

The assessment of HRQOL in children typically lags behind that of adults. Many studies have not been structured (Casey et al., 1994) with investigators using their own criteria of HRQOL. Often, the structured measures represent only limited aspects of HRQOL such as play performance (Lansky et al., 1987) or physical impairment (Lovell, 1989). Further, some assessments have not been completed by the subjects themselves, but filled in by parents or even doctors (Stein & Jessop, 1990). Finally, some measures have not accounted for developmental aspects, where changes in abilities and roles during childhood and adolescence have not been considered.

An additional weakness of current QOL instruments is that they are unable to differentiate between positive and negative QOL measures (Hyland, 1998). Positive (satisfaction) and negative QOL (dissatisfaction) have low correlation and are believed

to result from different causal pathways (Delongis et al., 1982). For example, an asthma patient who copes with their illness by avoiding activities that are likely to trigger asthma, will demonstrate low measures of negative QOL. However, this behaviour will impact upon positive life experiences associated with the disease and result in a poor positive QOL. Current QOL instruments generally provide a measure of dissatisfaction (negative QOL) rather than satisfaction, and are therefore limited in their assessment of the patient's subjective experience.

1.7 Adherence

"Adherence" has been defined as the extent to which a patient fulfils the intention of the prescriber in taking medication (McGavock, 1996). Used in a broader context, it refers to the extent to which the patient fulfils the intention of their health provider in relation to medication taking but also the adoption of health behaviours. It is regarded as the interface between effective therapy and effective disease management. Classification of patients into adherers or non-adherers implies all-or-nothing behaviour. However, Krause (1991) argues that the concept of adherence should be based on the level of adherence required to achieve a therapeutic response.

Despite vast improvements in asthma care over the past 25 years, there has not been a corresponding reduction in the morbidity and mortality associated with asthma (Rand, 1998). It is speculated that non-adherence is one of the major factors contributing to this. Non-adherence has been documented across regimens (trials of tablets and metered dose inhalers – Christiannse et al., 1989; Tashkin et al., 1991), across severity of the disease (Mann et al, 1992), and across the life-span (Baum & Creer, 1986; Chmelik & Doughty, 1994). Adolescence is characteristically associated

with poor adherence across chronic illnesses where a number of studies have demonstrated that approximately 50% of adolescents with chronic illnesses do not comply with recommended care (La Greca, 1990; Lemanek, 1990).

The remainder of this account outlines current research into adherence. Initially, it addresses the issue of adherence within a broad context, illustrating the methodological issues associated with measuring adherence, and highlighting general factors that have been associated with non-adherence across illnesses and development. Finally, issues of adherence are discussed in relation to asthmatic adolescents.

1.8 Models of adherence: From Compliance to Concordance

Within the literature, there has been a gradual shift in perceptions of patient behaviour, and this has been marked by the use of the term "adherence" as opposed to "compliance". Many have adopted "adherence" as it recognises that patients do not simply follow the instructions of their doctor without question, instead "patient factors" such as health beliefs and choices play an important role. Essentially, this shift has taken place alongside a growing awareness of the complexity of adherent behaviours. For example, despite extensive efforts to improve patient adherence, there seems to be little evidence of sustained success (McGavock, 1996).

Marinker (1997) argues that non-compliant behaviour is no more deviant than compliant behaviour. He states:

"resistance to taking medicines is profound and pervades different cultures and categories of disease. It is instinctual and complex.....there is something morally and psychologically flawed in the very concept of compliance." (pp.747)

He draws attention to the functional relationship between the patient and doctor within the therapeutic consultation. The patient is described as bringing to the consultation their "health beliefs", informed by previous experiences, cultural and family factors. The doctor is described as bringing scientific evidence and technical skill. Marinker argues that within a model of "compliance", the role of the doctor is to provide a solution to the medical problem by overcoming or overwhelming the patient's health beliefs. Compliance therefore portrays the patient as a dependent to the doctor.

Marinker argues that the concept of compliance is out of date: *"...modern society calls for transparency of information and accountability..."* (pp.748). He proposes an alternative model of "concordance", which views the patients' and doctors' "health beliefs" as equally important in the doctor-patient interaction. Thus, the aim of the consultation aims at forming a therapeutic alliance, where the doctor helps the patient to make as informed a choice as possible about the diagnosis and treatment. It recognises that *"just as all prescribing is an experiment carried out by the doctor so all medicine taking is an experiment carried out by the patient"* (pp.748).

1.9 Measuring Adherence in Asthma Patients

Measuring adherence to medical regimens is fraught with difficulties. A variety of techniques have been developed, and each of them has limitations. More importantly, all adherence measures are subject to "reactivity effects", e.g. people are more likely to

behave in a socially sanctioned way if they are aware that their adherence behaviours are being monitored. Therefore, the results of studies that have focussed on measuring adherence may be misrepresentative and inaccurate. The following strategies for measuring adherence to asthma regimens are reviewed: self-report, parental-report, provider estimates, inhaler cannister weighings/prescription pick-up, microelectronic monitors.

Patient and proxy reports provide a simple, inexpensive and clinically feasible method of measuring adherence (Bond & Hussar, 1991). In addition, they are ecologically valid and techniques such as diary keeping provide detailed information on patterns of adherence behaviour. Reporting formats include global ratings (rating adherence over a specified time interval), diaries (self-monitoring of adherence behaviour), and structured interviews. Numerous studies, however, have confirmed that patients and their families over-estimate adherence in their report (Rand et al., 1992; Dekker et al., 1993). Measures of adherence to prescribed medication have been attained by comparing self-report with objectively measured inhaler use, where an electronic inhaler timer device has been used to calculate the exact time and dose of use. In Rand's study (1992) only 15% of the sample were labelled adherent by measures on electronic inhaler timer devices, whereas 70% claimed they were adherent. One reason for this disparity proposes that patients recall adherence behaviours inaccurately, remembering only emotionally laden or stimulating events. Another reason suggests that patients and their families deliberately overestimate in their reports as they strive to tell their physician what they want to hear (Johnson, 1995). In this way the patient/family protects their relationship with their provider, or at least avoids disapproval. The manner in which patients and their families are questioned about adherence is important. For example, questions which are non-judgemental, specific and

time limited are likely to yield more accurate information about adherence, as they are less likely to generate evasive and defensive reactions (Kaplan & Simon, 1990; Klinnert et al., 1997).

Health provider estimates generally involve global ratings by physicians or nurses of the degree to which their patients are adherent. There is some evidence that such estimates are more accurate than global estimates from patients or their parents (Rapoff & Christophersen, 1982), however in comparison with other techniques, they are still considered inaccurate. This is perhaps not surprising, as clinical judgements can become biased in a number of ways. In addition, it has already been illustrated that patients do not necessarily disclose about their adherence behaviours to their physician.

Weighing inhaler canisters, counting pills, monitoring the rate of prescription pick-up or using microelectronic monitors are all strategies of measuring adherence. In comparison to patient/family and provider reports these techniques provide a more objective measure of adherence. In addition they are all relatively uncomplicated and feasible for use in the clinical setting. However, these measures cannot confirm ingestion of the drug. For example, the weighing of inhaler canisters has been found to over-estimate adherence (Rand, 1992). Results from this and similar studies suggest that patients deliberately empty or "dump" their medication so that they appear to be adhering to their prescribed regimen. Such "medication dumping" has been observed across illnesses and tends to occur when adherence is being closely monitored.

In conclusion, the measurement of adherence poses a number of difficulties. However, by employing a variety of measures, not alerting the patient to the fact that

they are being monitored, and adopting a non-judgemental attitude towards questioning, researchers have tried to overcome some of the methodological difficulties.

1.10 Understanding Adherence Behaviour

Most studies into paediatric adherence have examined correlates or predictors of adherence through correlational/regression analyses or measuring between-group differences on variables thought to impact on adherence (see Figure 1.1). Negative correlates of adherence can be used (with some caution) to develop "risk profiles" and identify patients who are likely to be non-adherent.

1.10a Patient and Family Factors associated with Adherence

A significant focus of the literature has been into the investigation of patient and family factors. A number of demographic variables have been associated with adherence. For example, adherence has been positively correlated with socio-economic status (SES). Factors associated with low SES such as high rates of unemployment, single parent families, financial and personal stresses may make management of a chronic illness low priority. Poor family cohesion or communication has also been consistently associated with adherence difficulties (Christiensen et al., 1996).

Level of patient and parent illness knowledge has been considered an important variable within self-management behaviour and considerable efforts have been made to develop patient education programmes. There is conflicting evidence as to the efficacy of such programmes. Devine (1996), for example, reported an increase in asthma care following an educational intervention. In contrast, others have failed to show any

significant decrease in asthma severity or in the use of medical services despite changes in level of illness knowledge (e.g. Hilton et al., 1986; Jenkinson et al., 1988). In conclusion, it is generally agreed that illness knowledge is necessary for adherence. However, information alone cannot account for promoting behaviour change.

1.10b Disease and Regimen Factors associated with Adherence

Duration, course, and perceived severity of a disease have all been positively correlated with adherence behaviour. Across chronic illnesses, adherence deteriorates significantly over time, with non-adherence emerging on average 3.5 years after disease onset (Jacobson et al., 1990). Adherence is particularly difficult to sustain over asymptomatic periods in illnesses in which symptoms wax and wane (Rapoff, 1989). Symptom severity has not been positively correlated with adherence. For example, greater health problems and risk of hospitalisation has been associated with lower adherence to inhaled corticosteroids in asthma patients (Van Ganse et al., 1997). It is likely that lower adherence produces worsening of symptoms. Perceived severity is a more useful predictor (Rapoff & Barnard, 1991). For example, maternal perceptions of higher severity have been associated with adherence to medications for asthma (Radius et al., 1978).

Regimen factors such as regimen complexity, route of delivery and side effects of medication have all been positively correlated with adherence. Increased dosing frequency has been associated with decreased adherence across a range of different diseases and therapies. In a study of children with asthma, comparing reported and actual compliance for twice, three and four times daily use, non-adherence increased with dose frequency (Coutts et al., 1992). Adherence behaviours have also been found

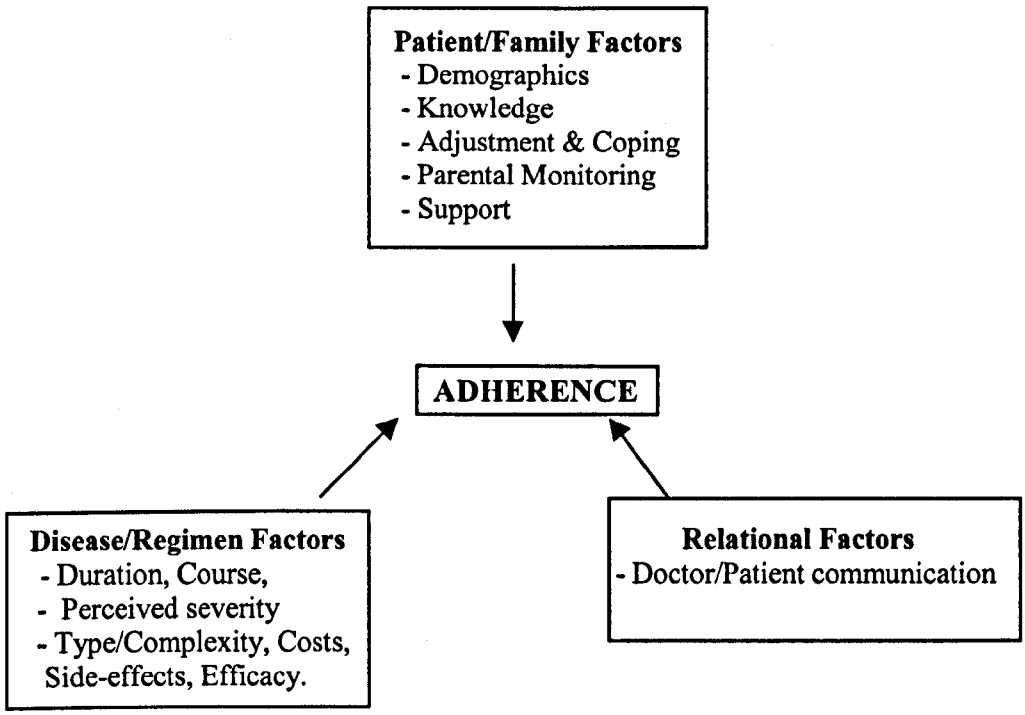
to vary as a function of route of drug delivery. Kelloway et al. (1994) in a sample of asthmatic adults and adolescents discovered that adherence behaviour increased with oral rather than inhaled medication. These results suggest that the optimal therapy/dosing regimens outlined in treatment guidelines may not be optimal for a given patient. Negative side effects from medications are also associated with greater non-adherence. For example, bad tasting asthma medications have been associated with poor adherence (van Es et al., 1998). Finally, perceived efficacy of the regimen has shown positive correlations with adherence. Higher levels of perceived benefits have been associated with better adherence to treatment in asthma and diabetes (Bond et al., 1992; Radius et al., 1978).

1.10c Doctor-patient relational factors associated with adherence

Over recent years there has been a growing awareness within the literature of the influence of doctor-patient relational factors on adherence behaviours. Within the psychotherapeutic literature such factors are widely recognised, and the concepts of transference and counter-transference have been described as operating between therapist and patient (Balint, 1964). Walsh, Hagan & Gamsu (2000) argued *"any evaluation of patient behaviour cannot solely be understood as a process of individualised meaning-making* (and especially) *within the field of chronic illness where there is an emphasis on the life-long self-management of illness – which imposes special demands on the sufferer and health care provider"* (pp.162). Specifically, the quality and ease of communication within the therapeutic relationship are particularly important factors. Where a patient feels that they don't have an open and trusting relationship with their doctor they are less adherent and likely to seek advice (Howard, 1991). Snaddon

and Brown (1992) found that coping well with asthma was facilitated by a trusting and mentoring relationship in which new learning could occur and vulnerability expressed openly.

Figure 1.1 Summary of Factors Associated with Adherence



1.11 Researching Adherence: Moving from Doctor to Patient Perceptions

As already illustrated within this account, a vast amount of research into adherence has gone into documenting the extent of the problem across different illness and age groups, identifying correlational variables and developing strategies to improve it. However, this research tells us very little about the reasons behind or causes of non-adherence. Adams, Pill & Jones (1997) argue that the inconclusive and contradictory results from studies that have attempted to understand this phenomenon can be accounted for by the *"absence of a theoretical framework, the domination of the*

perspective of the health professional and the failure to take into account the patient's views" (pp.189). Further, they argue that an individual's "meaning-making" about their illness has been minimized within the literature.

There is, however, a small growing literature that addresses the issue of adherence with prescribed medication from the client's perspective (Donovan & Blake, 1992; Stockwell Morris & Schulz, 1992; Morgan, 1996; Adams et al., 1997). Much of this work has been carried out using qualitative methods, such as in-depth interviews to explore the meaning of medication and medication-taking behaviour. These studies suggest that patients evaluate their illness and related behaviours in a wider context than a purely medical one. Essentially, they suggest that the decisions taken by the patient are rational and in the context of their beliefs, responsibilities and preferences. For example, Adams et al. (1997) explored adult asthma patient's attitudes to prophylactic medication using patient-centred rather than doctor-centred perspectives. This research concluded that attitudes to medication and medication practice are intimately linked to beliefs about their condition and coping strategies, which are in turn associated with the extent of their acceptance or rejection of the identity "asthmatic".

1.12 Models of Health Behaviour Change

A number of psychological models or general frameworks have been developed in an attempt to understand health behaviour and a selection of these are reviewed in relation to adherence. These models provide a conceptual basis from which to understand and investigate adherence, however many have not been rigorously applied to the field of adherence or asthma. Adherence can be conceptualised as a health

behaviour that relies on mechanisms similar to other health behaviours such as smoking cessation or regular exercise. Non-adherence can be viewed as a behaviour that increases health risk as it may lead to long and short-term worsening of the patient's condition (Keller, 1998).

The *Health Belief Model* (HBM: Becker et al., 1974; Figure 1.2) asserts that the decision of whether or not to engage in any health behaviour is a function of the perceived costs and benefits of doing so. According to this model such a cost-benefit analysis involves the consideration of two dimensions of threat posed by an illness: the individual's *vulnerability* to the illness and its *seriousness*, and the costs and benefits of engaging in any preventative behaviour. In the HBM, these costs are unspecified. In relation to adherence, this model would predict that higher rates of adherent behaviour would be observed in those who see their health problem as potentially serious, who see themselves at risk and perceive the benefits of following treatment to outweigh the cost of doing so.

The HBM has been adapted for use with a paediatric population. The Children's Health Belief Model (CHBM: Bush & Iannotti, 1990) includes similar dimensions to the HBM but also accounts for the role of the parent or caretaker. There is some correlational support for this model in relation to paediatric adherence models. For example, higher maternal-rated susceptibility, vulnerability and severity have been associated with increased adherence to medications in asthma (Radius., et al, 1978). In addition, higher perceived barriers, as rated by adolescents and parents, has been associated with poorer adherence for diabetes (Glasgow et al., 1986). Despite support for HBM it has come under some criticism. A specific limitation is that it only accounts for behaviour that can be predicted by attitudes and beliefs. Other factors such as social

contingencies, physiological factors and perceptions of self-efficacy need to be considered (Guerin, 1994).

The *Theory of Reasoned Action/Planned Behaviour* (TRA; Ajzen & Fishbein, 1980. Figure 1.3) is based on the assumption that behavioural intentions are the best predictors of voluntary actions. It proposes that intentions are determined by two factors. The first is the person's attitude towards the behaviour (health behaviour), which is based on two types of behavioural beliefs – belief about the likely outcome of the behaviour and the evaluations of these outcomes. The second determinant is of the subjective norm associated with the behaviour. This is based on two beliefs – those regarding others' opinions about the behaviour and the person's motivation to comply with these opinions. Thus, in addition to considering beliefs about the likely benefits of adherence, the TRA accounts for the influence of social factors. Cochran and Gitlin (1988) concluded that normative beliefs were the most potent factors in a patients' intention to take their medication, and that this intention then determined adherence.

The concept of *self-efficacy* (Bandura, 1977), developed out of social learning theory as part of a general theory of behaviour change, has been incorporated into both the HBM and TRA. Bandura maintained that behaviour change is directly linked to the modification of beliefs and expectancies. He distinguished two key sets of belief: *self-efficacy* – the belief that an individual can succeed at a particular task or with a particular behaviour; and *outcome efficacy* – the belief that the behaviour will result in a valued outcome. Two major pathways for self-efficacy influences on health have been proposed (O'Leary, 1992). One pathway involves its direct effect on the adoption of health behaviours such as adherence.

Figure 1.2 Diagrammatic representation of the Health Belief Model

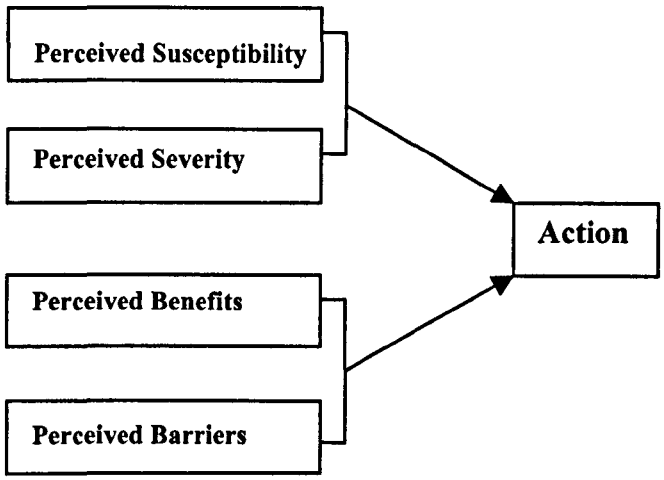
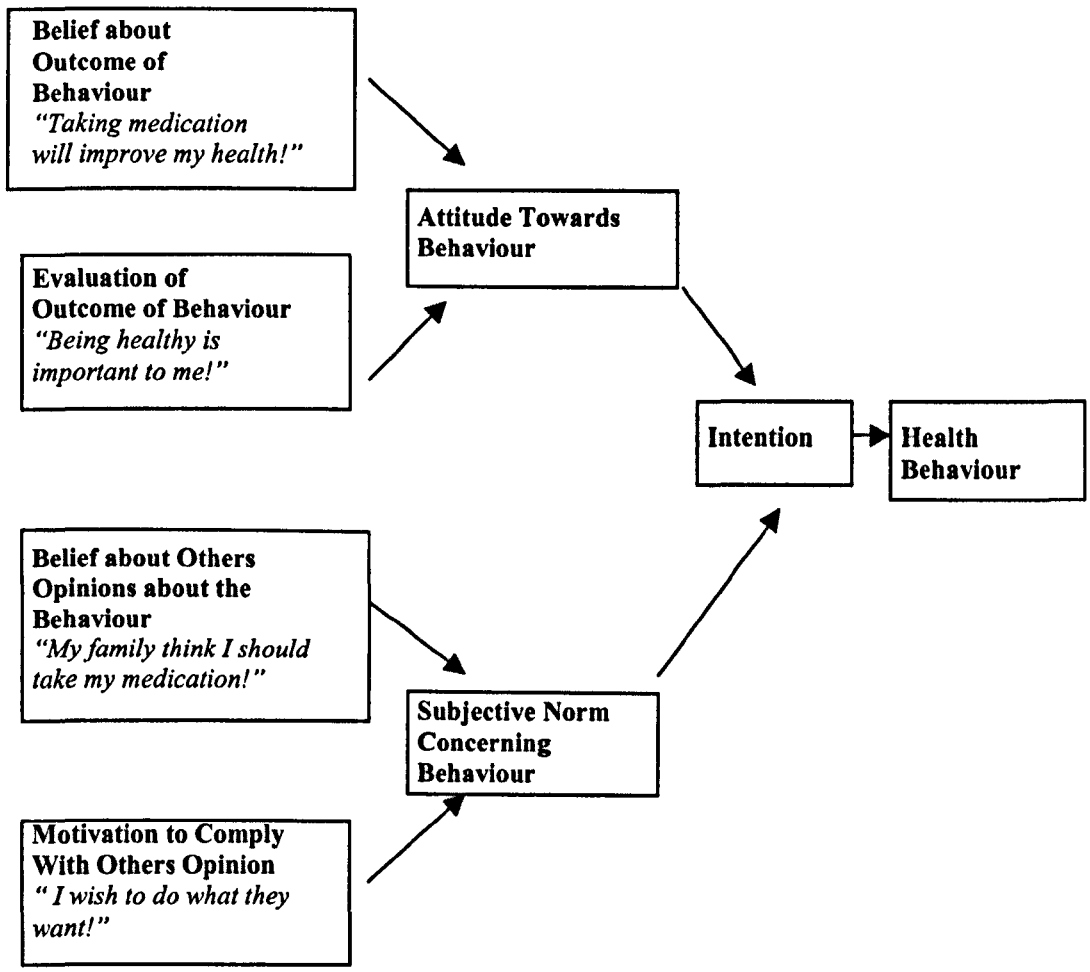


Figure 1.3: Diagrammatic representation of the Theory of Reasoned Action/Planned Behaviour Model



The other pathway concerns its effects on physiological stress. Those with high efficacy may experience less stress and negative emotional states that can exacerbate chronic illness.

Attribution Theory (AT) has also been considered within the remit of understanding health behaviour (Turnquist et al., 1988). AT is concerned with the way that people explain or attribute events. A number of dimensions have been identified such as stability (stable versus unstable influences), globality (global versus specific influences), universality (universal versus personal influences), and controllability (controllable versus uncontrollable influences). People's beliefs about their illnesses (causes and cure) can vary significantly along these dimensions, and are important for determining subsequent actions. *Health locus of control* seems to be particularly significant when considering adherence behaviour (Wallston et al., 1986). For example, strong beliefs in powerful others (e.g. doctors) have been associated with higher rates of adherence.

The *Stages of Change Model* (SCM; Prochaska & DiClemente, 1983. Figure 1.4) is a transtheoretical model that examines the structure of change underlying "problem behaviours". The model was originally developed within the field of addictions but has been applied to a variety of health behaviours such as exercise (Marcus et al., 1992); ultraviolet light exposure (Rossi, 1989) and mammography screening (Rackowski et al., 1992). SCM adds onto the intentional models of the HBM or the TRA as it integrates

motivational and behavioural aspects of behaviour change and also recognises the "process" and "temporal" dimensions involved. It explains "how" and to a certain extent "when" behaviour change occurs.

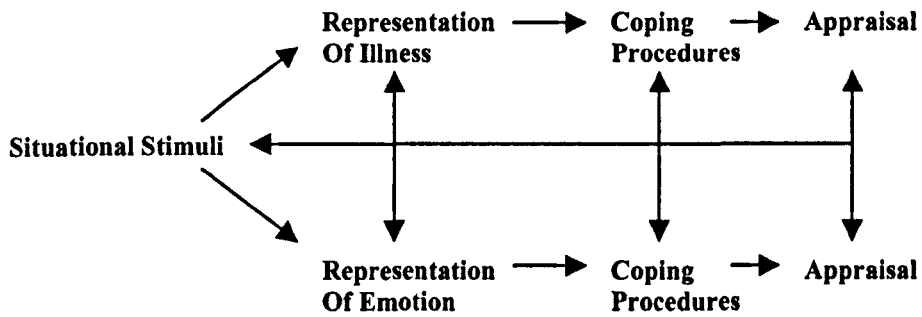
The *"stages of change"* represent ordered categories consisting of motivational readiness to change a problem behaviour. Five stages of change have been identified – precontemplation, contemplation, preparation, action and maintenance. Transition between stages is affected by a set of independent variables, including decisional balance (the benefits and barriers of the change) and self-efficacy. Essentially the model predicts that individuals will progress through the stages with periods of relapse that will be seen as regression to earlier stages. The *"processes of change"* are the dimensions that enable the understanding of how changes in attitude, intentions, and behaviour come about.

The validity of the SCM for understanding medication adherence in asthmatics has not been empirically tested. Keller (1998), however, points out that the model may provide a useful framework within which to address adherence as it relies on similar mechanisms seen in the adoption and maintenance of other health behaviours that have previously been outlined by SCM.

Illness Representation Models (Myer et al., 1985; Lau et al., 1986. Figure 1.4) are concerned with the way that patients cognitively make sense of illness and health threats, and propose that subsequent behaviour is directly related to these representations. Leventhal and Cameron (1987) propose three stages to explain the regulation of behaviour during a health episode. The stages are cognitive representation

(development of a model of what is wrong, causes and consequences), action planning or coping (development of plans to deal with the problem) and appraisal (evaluation of efficacy of these plans). Representations are ever changing as they are modified following appraisal. The model also incorporates representations of emotions. An individual's representation about their illness can provide clear insights into their decision to adhere to treatment. For example, cognitive representations that one's illness is serious, of long duration and is amenable to cure may be associated with adherent behaviour.

Figure 1.4 Diagram of the Illness Representational Model



(Cited in Leventhal et al., 1997, pp. 21)

The *constructivist model* of psychological reactions to illness is based within the philosophical school of phenomenology. It proposes that people who are ill make sense of what is happening to them based on their past experiences. They are able to make predictions about future events, and these determine subsequent behaviours in relation to the illness. The constructivist model acknowledges that each person will construe their illness differently, whether or not they share the same diagnostic category. The *Theory of Personal Constructs* (PCT: Kelly, 1955) provides a theoretical and

methodological framework within which to address psychological reactions to illness from a constructivist orientation.

1.13 Adherence: Adolescent Perceptions

No authoritative work has yet been undertaken to explore adolescent's reasons behind their self-management behaviour. The majority of the studies that have attempted to develop hypotheses and theories about why individuals adhere or fail to adhere to asthma medical regimens have been based on adult populations (Donovan & Blake, 1992; Adams et al., 1997). The validity and utility of downward extensions of these hypotheses/theories to adolescents are questionable as they fail to address developmental needs, challenges and capabilities.

As previously outlined, the experience of a chronic illness during adolescence poses a unique set of challenges, and can have important long-term implications in relation psychosocial/emotional development. Adolescence is characteristically associated with poor adherence (La Greca, 1990; Lemanek, 1990), and this is believed to be a major contributor to asthma morbidity and mortality. The lack of a theoretical framework in which to understand adherence behaviour in this group, however, makes it difficult to guide research and health care practice. Therefore, the importance of addressing adherence in this population is evident.

One study has attempted to address the adolescent's perceptions of their self-management behaviour in relation to their asthma, and this provides a baseline for further work. The results of a series of focus group interviews with adolescent

asthmatics (Van Es et al., 1998) gave some insight into the reasons behind self-management behaviours. Specifically, the majority of their sample admitted that they did not always take their medication as prescribed. Failure to adhere to prophylactic medication was attributed to both intentional and unintentional factors. For example, many participants commented that they simply forgot to take it and required cues or reminders. Others made explicit decisions not to take their medication and weighed up the pros and cons of the behaviour. Linked to this was the issue of acceptance of the diagnosis. A minority felt ashamed about it as they felt like outsiders and different from their peers. These individuals attempted to disguise the fact that they had asthma. The reasons for not taking their medication included, not noticing the effect of the prophylactic medication; being non-symptomatic; not feeling like taking it; and leaving a bad taste in the mouth. In addition, the majority of participants from this study indicated that they were not always truthful about the management of their asthma in consultations with their doctor. Some were concerned that their parents would be informed, others felt unable to ask questions, feeling embarrassed or that the doctor may become irritated.

In conclusion, this study has highlighted a number of factors that impact upon adherence behaviour within an adolescent population and provides a basis from which to begin to address adherence in adolescence. However, the sample of participants in this study was very small and the researchers emphasise that their findings should be interpreted with care. There is clearly a need for further work into this area.

1.14 The Present Study

The purpose of this study is to address this apparent gap within the adherence literature and thereby to inform the development of a theoretical framework, which can assist health care practices. The project aims to address how adolescents make sense of their illness and self-management behaviours. Essentially, this project is addressing the meaning an individual makes about their illness and treatment. The constructivist approach has been chosen as the philosophical and methodological framework within which to do this. Personal Construct Theory and its related methodology is reviewed in Chapter 2, with reference to its use in a paediatric population and into investigating health behaviours.

CHAPTER 2

Methodology

2.1 Personal Construct Theory

Personal Construct Theory (PCT) views an individual as striving for personal meaning. Its central underlying philosophical assumption is "Constructive Alternativism" which proposes that all of our present perceptions, insights and understandings are open to question and reconsideration. Kelly did not deny the existence of a real universe, but asserted that an individual's view is only their interpretation of it. People are engaged in an active and ongoing process of making sense of, or construing, their world and their experiences within it. The formal theory was presented in the form of a fundamental postulate and eleven corollaries (Table 2.1).

Construing is an act of discrimination whereby an individual perceives similarities and repetitions in their experience. Such discriminations allow an individual to anticipate or make predictions about future events (*Construction corollary*) which in turn determines that individual's actions. Therefore all behaviour can be regarded as "testing out the predictions". Kelly's metaphor of "man the scientist" portrays the essence of the process of construing. Essentially, an individual is acting as a scientist, making hypotheses, testing them out and if necessary revising them on the basis of evidence collected.

Construing is not the same as 'thinking' or 'cognition'. We construe as we look, listen, feel, touch and taste. Behaviour and emotion are as much a part of the construing process. It has been argued that PCT attempts to dispense with the thinking-feeling

dichotomy (see Bannister & Mair, 1968, Bannister, 1977). It asserts an essentially 'cognitive' constructivist approach to emotions which points out the epistemic or perceptual interpretative aspects of so-called emotional behaviour.

Kelly proposed the "personal construct" as the basic building block to his theory, the unit of analysis about which an individual accesses the world. The *Dichotomy corollary* suggests that *a person's construction system is composed of a finite number of dichotomous constructs.* A construct arises from an awareness of a similarity and contrast between events (or elements). It also provides a means by which an individual can then discriminate future events. Each construct is bipolar - it has what is known as an 'emergent (elicit) pole' and a 'contrast (implicit) pole', and is based on the principle that one cannot tell that what one observes is anything specific without having something to contrast it with.

Constructs are the personal creation of the individual, and are totally unique to that person (*Individuality corollary*). A construct may have a verbal marker; however, the meaning derived from that marker by another individual may become distorted. The contrast pole of the construct helps to define it's meaning and should always be considered. Not all constructs have verbal labels. Kelly referred to 'unlabelled' constructs as preverbal, having emerged before the attainment of language.

The *Range corollary* states that a construct *is convenient for the anticipation of a finite range of events only*. Therefore it has a range of convenience and is best suited to a particular set of events or elements. Kelly hypothesised that the range of a construct narrows as an individual develops expertise in a particular area. Constructs also vary in their permeability for accommodating new events or elements (*Modulation corollary*).

A construct is considered permeable if it admits new elements and impermeable if it rejects them.

People not only differ in the way they construe, but also in the way they organise their constructions (*Organisation corollary*). Constructs are linked together in ordinal relationships. Those that are more concrete form the basis for more abstract constructs. A construct that is more abstract than another is said to *subsume* it, and is therefore *superordinate* to it. Laddering (Hinkle, 1965) is a technique designed to elicit superordinate constructs. A construct, which is subsumed, is said to be *subordinate* to the other. Pyramiding is one way of elaborating subordinate constructs. As a construct system grows and evolves, subsystems of construing develop (*Fragmentation corollary*).

Construct systems are continually developing and changing. Kelly employed the *Experience corollary* to describe the change in a construct system and the *Choice corollary* to explain the way in which a construct system develops. Bannister and Fransella (1986) proposed that "people are in the business to anticipate events and if they do this by developing personal construct systems, then they will move in those directions which seem to make most sense, that is directions which elaborate their construct system"(pp.17).

Table 2.1: Fundamental Postulate and Corollaries

Fundamental postulate: A person's processes are psychologically channelized by the ways in which they anticipate events.
1. ***Construction corollary:*** A person anticipates events by construing their replications. 2. ***Individuality corollary:*** People differ from each other in their construction of events. 3. ***Organisation corollary:*** Each person characteristically evolves, for their convenience in anticipating events, a construction system embracing ordinal relationships between constructs. 4. ***Dichotomy corollary:*** A person's construction system is composed of a finite number of dichotomous constructs. 5. ***Choice corollary:*** Persons choose for themselves that alternative in a dichotomised construct through which they anticipate the greatest possibility for the elaboration of their system. 6. ***Range corollary:*** A construct is convenient for the anticipation of a finite range of events only. 7. ***Experience corollary:*** A person's construction system varies as they successively construe the replication of events. 8. ***Modulation corollary:*** The variation in a person's construction system is limited by the permeability of the constructs within whose range of convenience the variants lie. 9. ***Fragmentation corollary:*** A person may successively employ a variety of construction systems which are inferentially incompatible with each other. 10. ***Commonality corollary:*** To the extent that one person employs a construction of experience which is similar to that employed by another, his or her processes are psychologically similar to those of another person. 11. ***Sociality corollary:*** To the extent that one person construes the construction processes of another, they may play a role in a social process involving the other person.

2.2 The Repertory Grid

The Repertory Grid Technique (RepGrid) is a method for representing the ways a person thinks and feels or experiences their world and other people. It was originally seen as an integral part of PCT (Kelly 1955, pp xiv-xv), however it may be used without reference to the theory although it is implicitly grounded within it. Bell (see Neimeyer and Neimeyer, 1990) focussed on the product of the RepGrid procedure rather than the

task, and defines it as "*a set of representations of the relationships between a set of things a person construes* (the elements) *and the set of ways that person construes them* (the constructs)" (pp.26). A representation may be in the form of a tick, a ranking or a rating. The technique offers the flexibility and the individual focus characteristic of projective techniques, while retaining the precision and quantifiability of standardised tests.

2.2a Administration of the Grid

The first step in the RepGrid procedure is to elicit a list of 'elements' or aspects of experience from the subject. Although these elements are often people, they may be relationships (Ryle and Lunghi, 1970), facets of the self (Neimeyer et al., 1983a), situations (Parker, 1981), or any other aspect of a subject's world. As a result there are numerous options available to an investigator in selecting elements. Winter (1992, pp 22) comments that all elements selected for a grid should be within the "range of convenience of the construct subsystem with which the investigator is concerned" and that this is unlikely to be seen in a set of elements which are very heterogeneous. Yorke (1985) supports this notion and suggests elements should be selected with a particular purpose in mind otherwise they will produce 'statistical noise'. In summary, for an element set to be meaningful to a grid it must relate to the construct subsystem that is under investigation.

Elements are then used to elicit constructs and a number of different methods by which this can be achieved have been developed. The traditional triadic method has frequently been employed for research purposes. Typically, the subject is presented with

3 of the elements and is asked in what important way two of them are alike but different from the third. For example, if a subject says that two elements are similar because they are both *"outgoing"*, they are then asked to describe the third element or the opposite to them of *"outgoing"*. They may say, for example, *"shy"*. Therefore a bipolar construct has been elicited, where *"outgoing"* represents the emergent pole, and *"shy"* represents the contrast pole of the construct. This is represented as *"outgoing – shy"*. The procedure is then repeated with another triad of elements, and is continued until a range of constructs has been elicited. Essentially the Rep-Grid procedure elicits a representative sample of the constructs that an individual uses to interpret and predict a certain aspect of their experience.

The assessment procedure finishes at the elicitation phase if the content of the subject's constructs defined solely by their verbal labels, are only of interest. Grids are used to amplify the meanings of the constructs for the individual and illustrate the relationships between constructs. In completing the grid, the subject sorts all the elements in terms of all the constructs that have been elicited. There are various ways in which this can be achieved. The common method asks the subject to rate or rank the elements in terms of each construct. The end product of the grid procedure is a matrix of numbers, or ticks and blanks.

2.2b Analysis of the Grid

Various methods of analysis can be applied to the grid matrix. The most straightforward involves examining the nature of the constructs and elements elicited. Kelly (1955) noted that the superordinancy of a construct can be indicated by its

repetition in different triads, where ambivalence is reflected by two or more constructs sharing the same pole. A content analysis of elicited constructs provides another strategy by which to examine constructs. Several systems of construct categorisation have been developed (Landfield, 1971; Neimeyer et al., 1984).

Mathematical analyses of the grid matrix provide information about the relationships between constructs and elements. This can be achieved by simply 'eyeballing' the grid matrix, however quantitative analyses give a more precise picture. A number of computer programs are now widely available for analysis of grid matrices. Gridlab (Walter, 1998-2000) has been employed for the purpose of this study and is based upon the INGRID program (Slater, 1977). A description of the Gridlab computer package and its output is provided in Section 4.31.

2.2c Stability of Grid Scores

As has been noted by Bannister and Mair (1968), Kelly scoffed at the traditional notions of reliability and validity, reportedly defining reliability as *"that characteristic of a test which makes it insensitive to change"*, and validity as *"the capacity of a test to tell us what we already know"*. Slater (1965) points out that the common methods for assessing reliability and validity were designed for nomothetic tests, and are therefore inapplicable to the repertory grid which is an idiographic (emphasising individuality) technique. However, totally brushing aside conventional approaches surely leads to "a slippage of anything goes" (Yorke, 1985, pp.397).

Reliability of the repertory grid is concerned with whether the procedure is able to reveal stable features of a person's style of construing. It has been argued that if a grid does elicit significant features of an individual's construing, then grids completed by the same individual at a different time should show some stability (Sperlinger, 1976). A number of studies have demonstrated this. For example, Bonarius (1965) in a review of the literature found test-retest correlations in the region of 0.8. Other researchers report a similarity in the constructs elicited at different times even when different elements have been employed in the elicitation procedure (Fjeld and Landfield, 1961: Sperlinger, 1976).

Research examining the stability of general structural features of construing provides evidence of an increase in the level of interrelationships between constructs from test to retest (Bannister et al., 1971). These findings support the view that the RepGrid technique helps respondents gain insight into the way they construe. Studies of stability in the pattern of construct relationships over time have yielded reliability coefficients ranging from 0.6-0.8 (Fransella and Bannister, 1977). As might be expected from a test that is sensitive to individual developmental change, the reliability coefficients are reduced with increasing length of test/retest interval (Lansdown, 1975).

The dynamic reliability of the RepGrid approach is indicated by Salmon's review of the research on the development of construing (Salmon, 1976). This review concludes that the central feature of the development of construing is an increase in the organisation of the construct system. The degree of stability of an individual's construct system over time is significantly dependent on its 'validational fortunes'. Research has shown that invalidation of construing leads to a loosening of the construct

interrelationships, where validation leads to a tightening of construct interrelationships (Bannister, 1963; Crockett and Meisel, 1974; Cochran, 1977).

Other areas of research into the reliability of the RepGrid technique have focused on addressing the procedures used for elicitation of constructs and elements. One such area has been upon the comparison of grids that have been formed using supplied versus elicited constructs and elements. While some studies have found little difference (Metcalfe, 1974; Coleman, 1975), Adams-Webber (1979) found greater differentiation when elicited rather than supplied constructs were used. Therefore, there is some support for the notion that grids using elicited rather than supplied constructs and elements provide a more accurate representation of an individual's construct system.

More recently, research has focussed on assessing the stability of constructs elicited and their structure using different elicitation techniques. A variety of different techniques for construct elicitation have been developed. In brief, the traditional triadic elicitation procedure involves generating bipolar constructs by comparing and contrasting a triad of elements. The dyadic elicitation procedure (Keen & Bell, 1983; Landfield, 1971) differs from the triadic method as it asks an individual to only two elements when generating constructs. The monadic procedure asks the person only to consider a single element. It is generally thought that using fewer elements gives the participant a less confusing task, and is therefore more appropriate to use with children (Salmon, 1976).

Caputi and Reddy (1999) compared the triadic and dyadic methods of construct elicitation in terms of the kinds of constructs elicited by each approach, and the

structural properties of those constructs. The study concluded that personal constructs are "elicitation method dependent". Specifically, the triadic method elicits construct sets that are more cognitively complex and more meaningful in that they are better able to discriminate between elements. They also found that the triadic method elicits a greater number of antonym construct pairs (e.g. the implicit pole represents the true opposite of the emergent construct pole). Finally, their study did not find a high level of construct similarity across the two methods of elicitation. In summary, their study suggests that qualitatively different constructs are elicited by the two methods. They argue that this has important implications for researchers. For example, where a dyadic elicitation method is employed because it is simpler, a researcher should be aware that they may be eliciting less cognitively complex constructs.

2.2d Validity of Grid Scores

The validity of the RepGrid technique is concerned as to whether the elements and constructs elicited are appropriate representations of the ways the respondent is thinking about the things in question. Validity has been addressed in a variety of ways. Slater (1974) has provided a method of assessing the significance of an individual grid by testing the null hypothesis, that it is indistinguishable from a grid constructed with random numbers (quasi-grids). He concluded that the experimental grids are rarely comparable to 'quasi-grid' providing the constructs are meaningful to the subject, and the elements are within their range of convenience.

The internal validity of RepGrid measures of a construct system has been thoroughly examined by Fransella and Bannister (1977). They have shown that

independent statistical measures of associations between constructs in individual grids give highly similar results. These measures include Cluster Analysis, Principle Components Analysis and Factor Analysis using a variety of criteria for rotation of axes.

Other studies have been concerned with the predictive validity of the grid. Kelly (1955) indicated that the RepGrid is predictive of behaviour. He observed that grid results were reliably matched with subject's role-play performances. Subsequent studies have investigated the capacity of the grid to predict aspects of social behaviour. For example, Knowles and Purves (1965) were able to differentiate subjects into high and low "conditionability groups" in a conditioning experiment, based on the results from their grids. RepGrids have also been used to predicted voting behaviour (Fransella and Bannister, 1967) and preferences for universities (Reid and Holley, 1972). Salmon (1969) however, was less successful in predicting the conformity behaviour of a group of children based on the results from their grids.

2.3 Laddering

In addition to the RepGrid, the laddering process is a useful tool for amplifying the meaning to an individual of their ways of construing. The laddering technique (Hinkle, 1965) is a formal and systematic method for mapping out the progressively more superordinate implications of a person's personal constructs. It therefore highlights the interrelationships between constructs and facilitates the investigation of a construct system, complementing and extending upon the information provided by the RepGrid.

2.4 PCT: Working with Children and Adolescents

PCT offers a unique methodology from which to investigate the way in which young people view their world. Typically, research has sought to understand the experiences of the child from the inquirer's frame of reference, for example collecting evidence from observations of behaviour, structured questionnaires or semi-structured interviews. Essentially, all the responses obtained by these methods will be embedded within the context already given, about which the child has not been consulted. Such approaches might be considered as ways of understanding children, but not, as Ravanette (1977) argues, as *"ways of understanding children's understanding"*. In PCT the researcher is interested in investigating the child's view rather than proving or falsifying a particular hypothesis. The researcher's questions develop out of the child's construing, and are therefore set within the child's own context.

There are important considerations to be made when using PCT with young people because of the level of abstraction that is required in the elicitation of constructs and the use of the grids. As for all people, the words used by a young person in defining a construct will hold a particular meaning for them (Ravenette, 1977). A particularly useful way in helping to clarify meaning is the use of pyramiding and laddering as described in Section 2.3.

2.5 PCT: A Developmental Theory

For Kelly, as for all developmental theorists, development occurs within the context of time. The person is "assumed at the outset to be.....a form of motion" (Kelly,

1955, pp. 47-48). PCT is, however, argued to be incompatible with other stage theories of development (e.g. Piaget's cognitive developmental theory, Erickson's psychosocial developmental theory) (Vaughn & Pfenninger, 1994). Specifically, PCT denounces the 'inevitability' and 'unidirectionality' characteristics of development that other stage theories embrace. PCT emphasises that people are not compelled by their circumstances or biology to behave in any given way, but instead choose alternatives according to the manner in which they actively construe circumstances. As stated in the Choice corollary, an individual moves towards changes that appear to offer growth from his or her personal point of view. Stage theories, on the other hand, represent an extraspective position, in which personality is viewed from the outside, as a content moved along according to inevitable organic processes.

Although PCT is arguably incompatible with stage theories, it can be used in conjunction with them. Constructs or construct organisations may form commonalities in groups of people who share similar life span issues (e.g. Berzonsky & Neimeyer, 1988). The Commonality corollary suggests that where an individual construes events similarly to his peers, the individual's psychological experience will show commonality. In relation to this thesis, PCT can account for differences and commonalities in construing between the participants who are all considered to be at the same stage of development.

2.6 The Unique Experience Of Illness

As previously reviewed, when trying to the understand illness experiences of a young person, research has focused on questioning those who share the same diagnostic

label, and has considered other factors such as developmental age and familial relationships. Although such classifications are useful, these analyses do not account for the unique way in which each young person construes their experience and the meaning it holds for them.

As already outlined, according to Kelly there are external realities with which people have to contend. Individuals do not, however, necessarily face the same objective challenges; instead they interpret their worlds. Sharing a diagnosis gives no guarantee that experiences of the same illness are identical. In Kellian terms, individuals are in the business of making sense of their illness. Without an understanding of how an individual construes their own illness, their actions in relation to it may appear senseless and incomprehensible. Therefore PCT provides a theoretical and methodological framework within which to investigate the unique experience of the child in relation to their illness and in which to understand related behaviours such as adherence.

2.7 "Symptom Implication"

Previous studies have provided valuable insights into how patients become stuck in a particular style of construing. PCT predicts that a client will only relinquish adherence to identification with their symptom if their constructs relating to it become less superordinate (i.e. less central to their view of the world) compared to those relating to being symptom-free. Essentially the "symptom" has been considered as "providing a way of life" (Fransella, 1972) to which the patient adheres in the absence of a viable well-defined alternative.

Some evidence for this view has been provided from intervention studies with stutterers and anorexics. Specifically, the greater the implication of being symptom-free the more likely the client was found to respond to treatment (Fransella, 1972; Fransella & Button, 1983). Similarly, long-stay psychiatric in-patients who held highly elaborated construct system about life outside the hospital were more likely to adapt to life out of the hospital (Winter et al., 1996). In a study of chronic low back pain sufferers, subjects for whom the element *'self in pain'* was more meaningful than *'self without pain'* were more likely to respond to a conservative physiotherapy programme (O'Farrell et al., 1993). In other words, clients who held superordinate constructs relating to their symptom were only likely to find meaning, and respond to, a therapeutic approach which focussed upon their symptom.

In addition to the issue of superordinacy or number of implications, the nature of the implication is also important. Symptoms have been found to have positive implications or payoffs for subjects in studies of obese people (Leitner & Grant, 1982) and depressives (Rowe, 1971). Tshudi's ABC model (1977) provides a framework in which to address this issue. Essentially, it helps the individual clarify the positive and negative implications of 'having the problem' and 'not having the problem'. For example, an individual may see himself or herself as 'depressed' (**a1**), but wish to see himself or herself as 'not being depressed' (**a2**). Tshudi asks why a person who apparently wants to move along this axis does not actually change, and points out that this is because the problem (**a1**) has payoffs or advantages. The next step is to ask for advantages and disadvantages of **a1** and **a2**. Thus it is assumed that there are advantages of being at **a1**, and disadvantages of being at **a2**. This has been named the "implicative dilemma" (Hinkle, 1965).

This research highlights an interesting issue in relation to the current thesis. One prediction is that for a population of asthmatics the symptom "having asthma" will have more implications and therefore be more meaningful to the subject than "not having asthma". It can be hypothesised that asthma, therefore, provides a "way of life" and a way of functioning. Further, it is not inconceivable to recognise that there may be some positive implications for the asthmatic to have their symptom, or some negative implications to being "symptom-free".

2.8 Limitations of PCT

Despite the strengths of this methodology, there are limitations to consider. Firstly, RepGrids need to be tailor made. The validity and reliability of grid methodology and interpretation need to be assessed on an individual basis. Secondly, a grid is only a partial record of a person's perspective and other theoretical models may be equally useful. In addition it is only a "snapshot" of a system that is in continual motion. Thirdly, caution must be taken when interpreting a grid as the verbal labels may not necessarily reflect the actual meaning of the construct. Any interpretation of an individual's construct system by another person is likely to lead to some distortion, as the construct system of the other person will interfere with that interpretation. Another limitation of using PCT is that because it focuses on individuals it is difficult to apply a rigorous quantitative analysis of the results. Finally, there are ethical considerations. Self-revelation can be disconcerting and care needs to be taken to ensure that people do not feel disempowered or vulnerable. All of the above issues are relevant in any area of human research, and perhaps a strength of this methodology is that these considerations are explicit.

CHAPTER 3

Aims and Hypotheses

3.1 Aims

The current thesis is an exploratory investigation into understanding self-management or adherence behaviour within an asthmatic adolescent population. The central research question asks:

> "What is the experience of having asthma and taking medication in an adolescent population?"

Aim 1: To investigate the experience of 'having asthma' and 'taking asthma medication' in an adolescent population. This is achieved by:

a. Investigating the construal of 'having asthma' and 'taking medication'.

b. Investigating the construal of the element *'self'* in relation to asthma experience and adherence behaviour.

c. Investigating the underlying themes that account for the results with relation to the experience of 'having asthma' and 'taking medication' in an adolescent population.

Aim 2: To evaluate the validity of the methodology employed in relation to assessing issues about having asthma and taking medication in an adolescent population. This is achieved by:

a. Respondent Validation.

b. Triangulation of data sources.

3.2 Hypotheses

Relating to Aim 1.a:

Hypothesis 1: The experimental hypothesis is that the construal of the element *'me with asthma symptoms'* is more meaningful in that it offers more implications than the element *'me without asthma symptoms'*.

Relating to Aim 1.b:

Hypothesis 2: The experimental hypothesis is that the construal of *'self'* in relation to having asthma is consistent with the construal of *'self'* in relation to adherence behaviour.

Relating to Aim 2.a:

Hypothesis 3: The experimental hypothesis is that the results from the Asthma Grid are meaningful to the participant and represent the way in which they construe 'asthma' and 'taking medication'.

Relating to Aim 2.b:

Hypothesis 4: The experimental hypothesis is that the results from the Asthma Grid are consistent with the results of the Semi-Structured Interview in relation to addressing issues of asthma experience and adherence.

Hypothesis 5: The experimental hypothesis is that measures of asthma status (ratings on a global asthma severity scale; the "symptoms" subscale of the PAQOLQ) are significantly correlated with measures of asthma status taken from the Asthma Grid (distance between the elements *'self'* and *'me having asthma';* distance between the elements *'self'* and *'child with asthma').*

Hypothesis 6: The experimental hypothesis is that measures of self-reported adherence indicated on a rating scale are significantly correlated with measures of self-reported adherence taken from the Asthma Grid (distance between the elements *'self'* and *'me taking medication';* distance between the elements *'self' and 'me when I forget to take medication/don't take as prescribed'*).

CHAPTER 4

Method

4.1 Selection of Participants

The participants were recruited through four General Practice surgeries from the geographical areas of East, West and Central Hull, which represents a mixed urban and industrial area. Participants were identified from the asthma registers of each practice based on the following criteria:

- The individual is between 13 and 18 years of age.
- The individual is currently prescribed reliever and preventative asthma medication. ("Reliever" is defined as any selective beta-agonist medication either in dry powder form or metered dose inhaler via any of the current delivery systems. "Preventers" are maintenance prophylactic treatment, i.e. any inhaled steroid either in dry powder or metered dose inhaler via any of the current delivery methods.)
- The individual is prescribed daily use of preventative medication, i.e. participants have a minimum level of asthma severity in the opinion of their medical practitioner.
- The individual has had a diagnosis of asthma for more than 1 year, and therefore has not recently been diagnosed.
- The individual has no other significant illnesses.

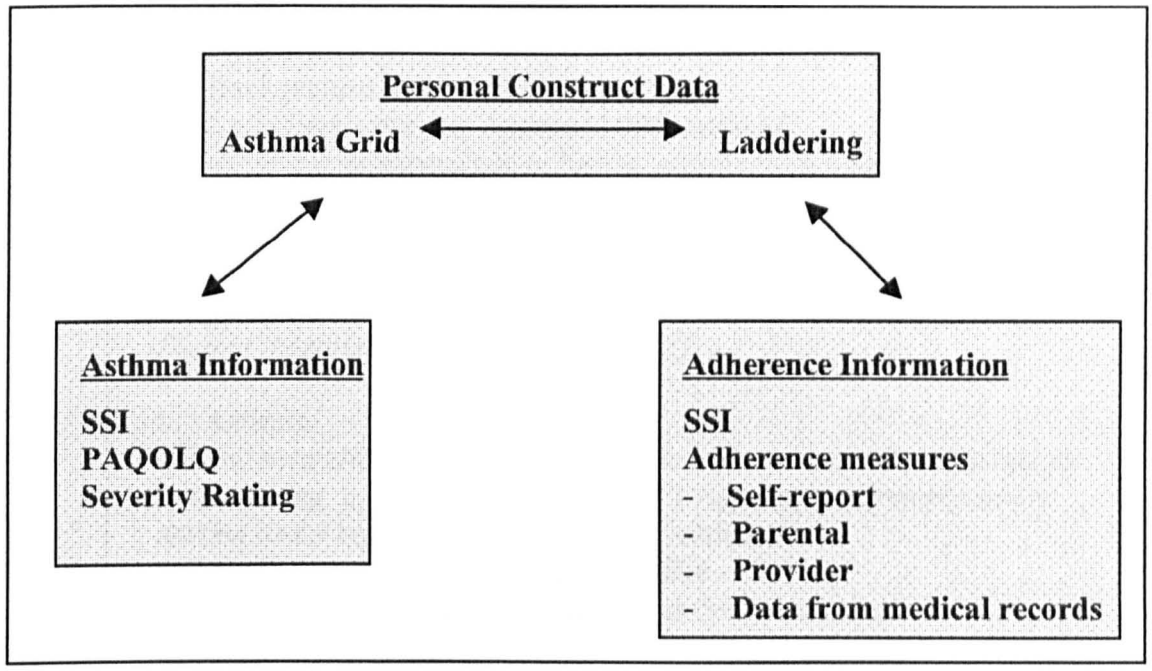
Participants were sent information about the project by their practice and were asked to reply to the principal researcher directly for inclusion into the study. 16 out of the 64 individuals invited to take part in the study responded, and 13 of these formed the

final study sample. 3 respondents did not take part for the following reasons: one respondent was self-excluded, stating that they didn't have time to take part; two respondents were excluded as they were no longer taking preventative medication and therefore did not meet the inclusion criteria. The total group consisted of 11 females and 2 males. The age range of the participants was from 13 to 17 years with a mean age of 15.15 years (SD=1.28).

4.2 Measures

A variety of measures were employed for obtaining information related to "asthma" and "adherence" issues. This section provides a description of these measures and explains their development and refinement. The methodology is shown in Figure 4.2a, which illustrates data sources and methodological links. Comparison of data sources, as illustrated by the arrows, provides a means of triangulation.

Figure 4.2a Overview of the study



4.21 Asthma

(a) Semi-Structured Interview (SSI)

The semi-structured interview was designed to address the participant's views about "having asthma" and "taking medication" within a current and historical context. The participant's parent was also invited to take part in the interview. Thus, the results from this interview provide a set of data that can be compared with sets of data obtained from different methods (i.e. personal construct data). The interview incorporated both closed and open questioning, and the order in which questions were presented to each

participant was open to modification. The interview schedule is shown in Figure 4.2b. It is broken down into the areas of background information; asthma issues; medication issues. Prompts and probes were developed with reference to the open questions, which enabled the interview to be directed to areas of interest. All interviews were audio taped (with consent from participant and parent) and transcribed. A summary of each participant's statements from the interview is presented in Appendix IV.

Figure 4.2b Semi-structured interview schedule

a. Background information

1. At what age were you diagnosed with asthma?
2. Describe your experience of having asthma from diagnosis to the present time. *(Probe on periods in which asthma has been severe/mild; associated feelings).*
3. Describe your experience of taking asthma medication from diagnosis to the present time. *(Probe on changes in treatment; associated feelings. Prompt: hospital admissions for asthma.)*

b. Asthma

4. How severe/mild is your asthma at the current time? *(Participants to answer using a rating scale 1-9, where 1 represents extremely severe asthma and 9 represents extremely mild asthma.)*
5. Describe your asthma at the current time.
6. What do you feel about your asthma at the current time?

c. Medication

7. What asthma medications are you currently prescribed? *(Prompt: reliever and preventer medications; doses and frequency.)*
8. Who takes responsibility for administering your medications?
9. What do you think about your medications?
10. How do you feel about taking your medications?

(b) The Paediatric Asthma Quality of Life Questionnaire (PAQOLQ: Juniper et al, 1996)

The PAQOLQ is an instrument that has been designed to measure the impact of asthma on the quality of life in children and adolescents. The instrument includes 23 items in the following three domains: activity limitation (A), symptoms (S) and

emotional function (E). Asthma symptomatology and level of functioning experienced during the past week were indicated by means of the "symptoms" and "activity limitations" subscales. Psychological variables associated with asthma over the past week were indicated on the "emotional function" subscale. Responses for each item were on a 7-point scale where 1 indicates maximum impairment and 7 indicates no impairment. The instrument is simple and easy to use and has been examined across age groups (7 years 0 months – 17 years 11 months) and across different severities of asthma.

The instrument has been shown to have high reliability and cross-sectional construct validity. Juniper et al., (1996) demonstrate high levels of test-retest reliability in subjects whose asthma remained stable (intraclass correlation coefficient = 0.95 for overall QOL). Similar correlations were seen across all domains and age groups.

Cross-sectional construct validity was assessed by correlating QOL scores with measures of asthma severity, and with a generic QOL score. Moderate correlations were found for all domains of quality of life and clinical outcome measures of beta-agonist use (S, r =-0.61; A, r = -0.62; E, r = -0.37), clinical asthma control (S, r = -0.51; A, r = -0.49; E, r = -0.30) and a generic health related QOL measure (S, r = 0.41; A, r = 0.53; E, r = 0.36). Juniper et al (1996) draw attention to the higher correlations for the symptom and activity subscales, and comment that these results are consistent with their predictions as the scales are "tapping into somewhat different aspects of quality of life". Similar results were seen across age groups. In conclusion, the PAQOL is a valid instrument for discriminating between patients on measures of QOL.

4.22 Adherence

Self and proxy- report measures are sensitive to social-desirability effects (Johnson, 1995). The way in which people are questioned about adherence is critical in the accuracy of the report. Non-judgemental questioning is likely to reveal more accurate information (Klinnert et al., 1997). In an attempt to increase the accuracy of report, the issue of adherence was introduced to participants in the following way.

> *"Many young people who have asthma are prescribed medication which they should take at certain times. It's quite rare that they take their medication as they should all the time. Sometimes they may take more than they are prescribed, sometimes they may take less, either because they forget to take it, or because they don't want to take it. Over the past 2 weeks have there been any occasions in which you have taken more or less medication than you should have?"*

The following measures of adherence were obtained:

(a) Self-report global ratings of adherence

Participants rated adherence behaviour on a scale of 1-9 where 1 represented "I never take my medication when I should" and 9 represented "I always take my medication when I should". This measure was obtained independently of the parent.

(b) Parental global ratings of adherence

Parents rated their perceptions of the participant's adherence behaviour on a scale of 1-9 where 1 represented "he/she never takes his/her medication when he/she should" and 9 represented "he/she always takes his/her medication when he/she should". This measure was obtained independently of the participant.

(c) Health provider global ratings of adherence

Health professionals rated their perceptions of their patient's adherence behaviour on a scale of 1-9 where 1 represented non-adherence and 9 represented adherence.

4.23 Selection of Personal Construct Theory Techniques

A pilot study was carried out with three individuals aged 13, 15 and 18 years respectively. In light of this, alterations were made to the methodology and these are detailed within this section.

(a) Construct Elicitation

Constructs were elicited from each participant using the triadic method of construct elicitation. Research has demonstrated that elicited rather than supplied constructs are more meaningful and provide a more accurate representation of the individual's construct system (Adams-Webber, 1979). Elements were provided rather than elicited from each participant. These were selected so that the construct elicitation procedure would sample the person's most significant constructs, having as their focus of convenience "implications of asthma during adolescence". The elements are displayed in Figure 4.2c.

The *"self elements"* (self, ideal self, self as was) were selected to elicit constructs relating to the self in the past, present and how they would like to be. Comparing the element "self" with all the other elements provides a self-identity matrix. Correlations between self and ideal self have frequently been used as a measure of self-esteem (Button, 1994). "Ideal self" allows identification of the value a person puts on a

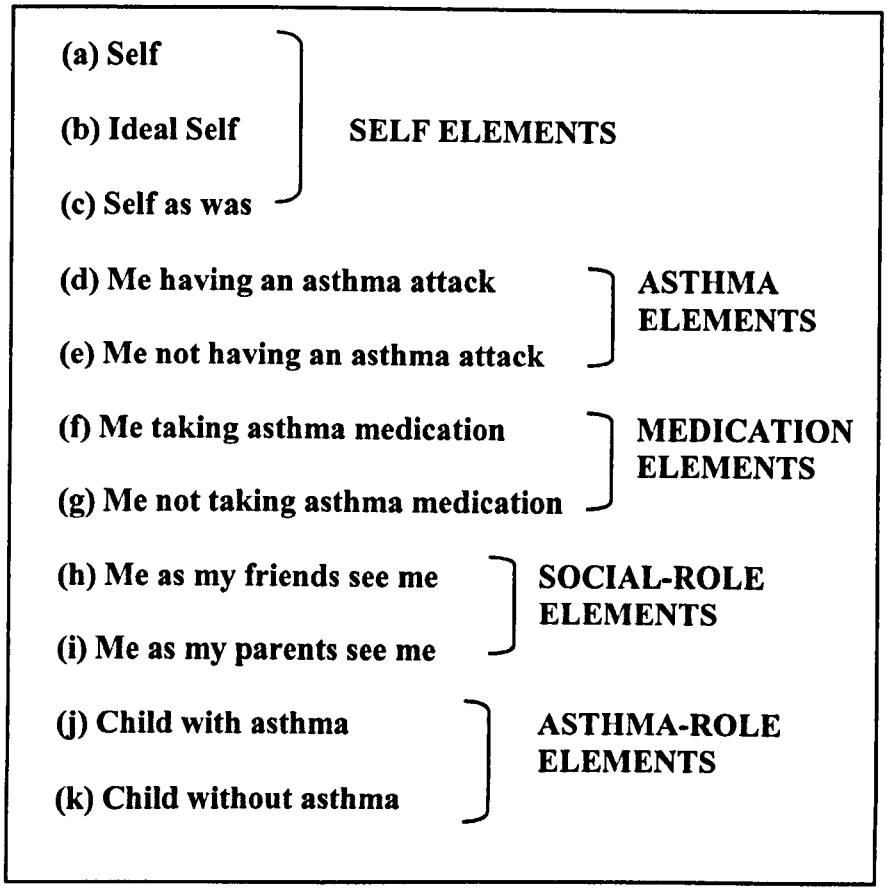
particular construct, and therefore allows mapping of whether a construct is positive or negative.

Elements selected for a grid should be within the 'range of convenience of the construct subsystem with which the investigator is concerned' (Winter, 1992. pp22). As the current study is specifically interested in the subsystems relating to the experience of having asthma and taking medication the elements *'me having (not having) an asthma attack'* and *'me taking (not taking) asthma medication'* were included. Such illness or symptom-specific elements have been used in previous studies. For example in a study of chronic back pain, the elements *'self without pain' and ' self before pain onset'* were used as a way addressing the construct subsystem of pain (Drysdale, 1989).

A major task for the adolescent relates to the development of increased autonomy and separation from parents, and increased identification or shared construing with a peer group. Research into the impact of a chronic illness over this developmental stage has implicated barriers to these processes. The elements *'as my parents see me'* and *'as my peers see me'* were included into the asthma grid as a means of addressing these issues.

For the elements *'child with asthma'* and *' child without asthma'*, participants were required to provide names for people they knew who fitted these roles. The provision of people to fit social role titles is a technique widely used in the elicitation of constructs as the construing of actual persons is more differentiated than the construing of social roles (Stringer, 1979). In this case, these elements were provided to obtain constructs from participants about other people who have or don't have asthma.

Figure 4.2c: List of Elements



Triads of elements for construct elicitation were composed from the list of elements (see Appendix I). On presentation of a triad of elements, participants were asked to:

- Choose the two elements in the triad which were most similar, and different from the third.
- State the *most important* way to them that the two chosen elements were most similar and therefore different from the third.

This was recorded as the emergent pole of the construct. They were then asked to say in what way the third element was different from the other two. This was recorded as the implicit pole of the same (bipolar) construct. 12 triadic combinations of elements were presented to each participant to give a total of about 12 constructs. In some cases

more constructs were obtained as the participant elaborated their thoughts and feelings. In other cases fewer constructs were obtained as the same construct was elicited from more than one triad.

(b) The Asthma Grid

Participants were asked to rate all 12 elements on each bipolar construct (using a 7 point scale with the emergent pole being 1 and the implicit pole being 7). A sample of an Asthma Grid is shown in Figure 4.2d. For an example of a completed Asthma Grid, see Appendix II. Therefore 12 ratings were assigned to each bipolar construct and this ensured that a reliable index of association (i.e. correlation coefficient) between constructs could be obtained from the analysis. The reliability of a correlation coefficients computed from less than 8 to 10 observations is questionable.

Figure 4.2d: A Sample from the Asthma Grid

Emergent 1 2 3 4	Implicit 5 6 7	Self	Ideal Self	Self as was	Me having an asthma attack
feel scared	feel calm	5	7	3	1
feel left-out, excluded	feel I am part of the group	6	7	5	4

(c) Refinement of Method Following Pilot Study

(i) Construct Elicitation

A primary issue of concern in relation to the pilot study was to address the utility of the triadic method of construct elicitation with an adolescent population. This technique necessitates the use of abstract cognitive abilities as it asks participants to

compare and contrast concepts such as "self". More simplistic methods of construct elicitation have been developed (Keen & Bell, 1983; Landfield et al., 1971), however research has suggested that such techniques produce qualitatively different constructs which are less cognitively complex and meaningful (Caputi & Reddy, 1999).

The participants within the pilot were 13, 15 and 18 years of age and represented the lower, middle and upper ages of the intended sample population. Each participant commented that he/she had understood the "construct elicitation" exercise and were able to produce a number of constructs. The youngest participant, however, commented that she had found difficulty comparing some of the more abstract triads (such as *'self'*, *'self as was'* and *'ideal self'*). On the basis of participant comments and observations from the pilot, the following refinements were made:

- The use of "element cards", where elements are presented to the participant on cards that can be physically arranged. This focuses attention and simplifies the task.

- Simplification of instructions and language. For example, the element *'self'* was relabelled *'me as I am now'*; the element *'self as was'* was relabelled *'me as I used to be when I was younger'*. A particular change was made in relation to the element *'me having an asthma attack'* as all participants commented that they didn't have asthma attacks! The more appropriate label of *'me having asthma symptoms'* was devised.

- Modification of the order of presentation of the element triads. For example, concrete triads (such as *'me as I am'*, *'me with asthma'*, *'me without asthma'*) were presented earlier than the more abstract triads (such as *'me as I am'*, *'me as I used to*

be', 'me as I want to be'). It was assumed that the concrete triads would introduce the task, making it easier to complete the more abstract items.

(ii) Completion of the Grid

All participants commented that this part of the interview was the easiest; however, as one person pointed out *"it was boring"*. One observation during this part of the process related to confusion about the element *'me not taking asthma medication'*. Following questioning of some ratings on this element it became clear that it was being confused for "me when I forget to take asthma medication/don't take medication as prescribed". The intended meaning of the element was "me at the times when I don't have to take medication". Therefore, the original label was replaced by the elements *'me when I forget to take my medication or don't take my medication as prescribed'* and *'me at times when I don't have to take medication'*. Figure 4.2e shows the final list of elements used for the main study.

Figure 4.2e Refined List of Asthma Grid Elements

(a) Me as I am now (Self)
(b) Me as I would like to be (Ideal self)
(c) Me as I used to be (Self as was)
(d) Me with my asthma (symptoms)
(e) Me without my asthma (symptoms)
(f) Me taking asthma medication
(g) Me not taking asthma medication
(h) Forget to take asthma medication/ Don't take as prescribed
(i) Me as my friends see me
(j) Me as my parents see me
(k) Child with asthma
(l) Child without asthma

(iii) Validity of the Asthma Grid

Following analysis of the grids using the Gridlab package, the participants were provided feedback of the results. They were asked to rate the accuracy of the feedback in relation to how they felt about their asthma and taking asthma medication using a scale of 1 to 5 where 1 represented "very accurate". All participants gave ratings of 1 or 2 suggesting that they felt that the technique had accurately elicited information that represented how they felt about their asthma and their adherence to medication.

(iv) Provision of Anchor Constructs

Following the pilot it was decided to include a number of supplied anchor constructs chosen in relation to issues of interest from the literature. Participants were provided with a single pole, and were asked to produce the contrast pole. These anchor constructs were:

- *"feel like a person with asthma"*
- *"feel different"*
- *"feel independent"*

(v) Laddering

This technique was incorporated into the main study as it provides a method of triangulation of grid results and brings with it greater ecological validity.

The following were selected for laddering:

- Ambivalent constructs – constructs which have both positive and negative implications (e.g. ideal self is rated at the mid-point of the construct). Ambivalent constructs represent an area of ambiguity and conflict within a construct system that is not necessarily demonstrated in the grid. The

laddering of these constructs highlights such areas of ambiguity and brings greater meaning to the grid and to an individual's behaviour.

- Constructs that appeared to be significant for the participant e.g. where the participant had difficulty verbalising the construct or displayed emotional reactions when stating them.

4.30 Procedure

The study received ethical approval from the Hull and East Riding Ethics Committee.

Participants were contacted by telephone following receipt of their responses indicating that they were interested in the study. The nature of the project was briefly described at this point, with specific reference to the time frame of the project, and what it would involve. Following confirmation that they were keen to participate, an initial appointment was arranged. A parent/guardian was asked to be present for this appointment. All were given the opportunity to choose the venue of the appointment, either at The University of Hull, or within their own home. All participants requested to be interviewed in their homes.

The initial part of the first session was spent with the participant and their parent. The following information was explained:

- The background of the researcher.
- The aims of the study: to look at what young people who have asthma think about their condition and their medication.
- What participation in the project would involve: two hourly interviews with the researcher, the types of questions asked, and the fact that their medical notes might be reviewed.
- Confidentiality: the information gained would be recorded anonymously and not fed back to their parents or doctor.

- Withdrawal from the study: that individuals could withdraw from the project at any stage.
- To answer any questions that arose.

This information was corroborated in a project information sheet that was provided. Written consent was obtained from each participant. Parental consent was also obtained for participants under 16 years of age. A copy of the consent form was provided to each participant, their GP and one was kept by the researcher.

The full assessment was completed over a minimum of two sessions. Both sessions were carried out in an informal style, however the instructions that were used, and the order of presentation of the assessments were standardised. The following represents the order of the tasks that were completed.

- Semi-structured interview: completed with the participant and their parent. All interviews were audio taped and transcribed.
- Participant and parent global rating scales of adherence: completed by each independently of the other.
- Paediatric Asthma Quality of Life Questionnaire.
- Elicitation of personal constructs.
- Development of the Asthma Grid.
- Laddering of constructs.

Typically, all the assessments up to and including the elicitation of personal constructs were completed in the first session. The second session was spent developing the Asthma Grid and laddering specific constructs.

4.31 Grid Analysis

All Grids were analysed using the Gridlab for Windows 95/98/NT (version 0.86) computer program (Walter, 1998-2000). Essentially, Gridlab performs similar functions to INGRID (Slater, 1977), one of the most detailed and widely used methods of analysing individual grid data. The output from Gridlab consists of the following data.

(i) Mean construct ratings across elements

This can be used as a simple measure of a subject's tendency to rate elements to one construct pole rather than the other (Winter & Gournay, 1987).

(ii) Percentage grid variation accounted for by a construct

This is calculated as follows: for each construct, the sum of squares of deviations from the mean is calculated. The total variations for all constructs are accumulated and the percentage contributed by each construct derived. This has previously been used as a measure of superordinancy (Bannister and Salmon, 1967). The greater the percentage variation, the more superordinate a construct.

(iii) Relationships between constructs

This is represented by correlation coefficients (i.e. Pearson's 'r') and angular distances. An angle of 0 degrees corresponds with a correlation of 1.0, an angle of 90 degrees corresponds with a correlation of 0, and an angle of 180 degrees corresponds with a correlation of –1.

(iv) Percentage sum of squares accounted for by each element

This is used as a measure of the importance of an element in a person's construct system. If the value is small, the subject has rated that element near to the mean on all constructs, suggesting an indifferent attitude. Conversely, a large value implies that the element has shown greater discrimination when constructs were rated on it and is therefore more meaningful. These calculations were used for addressing Hypothesis 1 (Section 3.2).

(v) Interelement distance

This is a measure of perceived similarity/dissimilarity of elements across constructs. The greater the distance between two elements, the greater the perceived dissimilarity. Distances are represented on an individualised scale, where a distance of 0 indicates that two elements are construed identically. Distances rarely exceed 2 and a distance of 1 would be expected by chance. The output provides parameters which indicate levels of significance.

(vi) Principle components analysis

The percentage variance accounted for by each component is listed. A high percentage variance accounted for by the first component indicates tightly organised and unidimensional ways of construing. Vectors and loadings of each element and construct onto each component are provided in the output. A visual representation of the subject's construct system is obtained by plotting the construct and element loadings onto the first two components. In general, elements in opposing quadrants of the grid can be considered most dissimilar, while those furthest from the origin are the most extremely perceived. The plot is not an accurate representation of an individual's construct system as it is based on

only the first two components. However, triangulation of the plot with various measures given in the output provides an adequate representation.

4.32 Debriefing and feedback

At the end of the second session, participants were debriefed about the study aims and methodology. They were asked about their views on their experiences of the interviews, with particular emphasis on the following areas:

- Ease or difficulty of different parts of the assessment.
- Validity: did they feel that the interview process had been successful in eliciting their thoughts and feelings about having asthma and taking medication?
- Levels of intrusion or distress: did they feel the interview was too intrusive? Had the interviews been distressing in any way?
- Request for further involvement: did they want to discuss the issues raised during the interviews further?

Individual feedback was provided to each participant on two occasions. Verbal feedback was provided at the end of the final session following an "eye-ball" analysis of the results. Written feedback was provided to each participant following formal analysis of the grid using the Gridlab computer package. The criteria used by which to give feedback are shown in Figure 4.3a. Participants were invited to arrange a detailed verbal feedback session if they felt they wished to discuss the results further. Participants' views about the accuracy of the feedback were obtained (evaluation of verbal feedback

was achieved in session; evaluation of written feedback was achieved from an "evaluation form" returned to the researcher, see Appendix III).

Figure 4.3a: Criteria for Asthma Grid Feedback

Each grid was analysed on an individual basis, attending to particular clusters of constructs and elements. However, a template was developed to structure and standardise the feedback given to all participants, and this is outlined below.

- Conceptual distances between *'self'*, *'ideal self'* and *'self as was'* and related constructs - addressing where they see themselves at the current time, how they used to be, and how they would like to see themselves.
- Clusters of constructs or elements around *'me with asthma symptoms'* - indicating issues associated with having asthma.
- Clusters of constructs or elements around *'me taking medication'* – indicating issues associated with taking medication.
- Relationship of *'self'* to *'me with asthma symptoms'* compared to *'me without asthma symptoms'*- indicating severity of asthma, or the extent to which they feel their asthma is "under control".
- Relationship of *'self'* to *'taking medication'*, *'not taking medication'* and *'forgetting to take medication/not taking as prescribed'* - indicating self-perceptions of adherence.
- Relationship of *'self'* to *'as parents see me'*, compared to relationship of *'self'* to *'as friends see me'* – indicating nature of social relationships.
- Relationship of *'self'* to *'child with asthma'* – indicating extent to which the participant identifies themselves as an individual who has asthma.
- Summary of the results from the laddering process.

CHAPTER 5

Results

The results are presented in accordance with the study aims described in section 3.1. Individual assessment profiles, including results from the Semi-Structured Interview (SSI), Asthma Grids and laddering data are presented in Appendix IV. A summary of the data is provided and presented under the following sections:

- Demographic results and descriptive statistics.
- Aim 1: Content /structure of Asthma Grid.
- Aim 2: Validity of the Asthma Grid.

5.1: Demographic Results and Descriptive Statistics

Table 5.1a provides a profile of the demographic details of the participants and all the measures taken in the study other than those involved in personal construct techniques. Demographic details include age, gender and age at diagnosis. Asthma status measures include participant ratings of global asthma severity and quality of life (symptoms, activities and emotions subscales). Adherence measures include participant self-, parent- and health provider- ratings of perceived adherence. A separate variable, indicating any hospitalisations for asthma over the previous two years, was extracted from the SSI. The table provides comparison material for subsequent sections.

Table 5.1b presents the median and inter-quartile ranges for the asthma and adherence measures given in Table 5.1a.

Table 5.1a Demographic, asthma and adherence measures for each participant.

Participants	Age (yr)	Gender	Age at diagnosis (yr)	Severity rating	"symptoms" QOL	"activities" QOL	"emotions" QOL	Self-Report Adherence	Parental-Adherence	Provider-Adherence	Hospitalisations
A	17	f	5	6	5	4.8	4.9	4	6	5	no
B	16	m	3	9	5.9	6.6	6.5	9	9	5	no
C	15	f	5	9	6.3	5	6.25	9	8	8	no
D	13	f	<1	6	5.5	5.2	5.37	5	3	4	no
E	16	f	1	8	3.3	3.6	4.25	8	8	4	no
F	13	f	2	8	6.2	6.2	5.25	8	8	9	no
G	14	f	3	8	3.9	2.8	3.5	7	5	7	no
H	16	f	1	5	3.8	3.8	5.25	5	3	6	no
I	16	f	1	5	4.9	4.8	5.87	8	8	9	no
J	14	m	2	6.5	4.7	4.6	4.75	8	9	8	no
K	17	f	15	8	6.2	6.6	6.87	7	8	7	no
L	16	f	15	9	6.9	7	7	4	2	1	no
M	14	f	2	9	5.7	6	5.7	8	9	5	no

Table 5.1b Median and inter-quartile ranges for asthma and adherence measures.

	median	Inter-quartile range
severity global rating	8	4
PAQOL "symptoms"	5.5	3.6
PAQOL "activities"	5	4.2
PAQOL "emotions"	5.37	3.5
subject adherence rating	8	5
parental adherence rating	8	7
provider adherence rating	5.5	8

The above tables indicate that for the sample, the participants do not rate their asthma as severe. The median rating on the severity global rating scale for the sample is 8, where a rating of 9 represents mild asthma and 1 represents severe asthma. The median ratings on the symptoms, activities and emotions subscales are 5.5, 5 and 5.37 respectively, where 7 represents low functional/psychological problems associated with

asthma. Participant and parental adherence median ratings are both 8, and indicate perceptions of 'good adherence'. The large range values, however, indicate some variability in these adherence perceptions across the sample. The provider adherence median rating is 5.5, and suggests that provider's perceive the sample to be poorer adherers than participants and parents.

Table 5.1c summarises the correlations between asthma measures taken from the global severity rating and the Paediatric Asthma Quality of Life Questionnaire (PAQOLQ) subscales. Nonparametric correlations were performed, as the data were ordinal in nature.

Table 5.1c Correlations between asthma measures

	severity	symptoms	activities
symptoms	rs=0.622 p=0.023*		
activities	rs= 0.526 p = 0.060	rs= 0.887 p=0.000**	
emotions	rs= 0.411 p = 0.160	rs= 0.798 p=0.001**	rs= 0.825 p= 0.000**

(Spearman's Correlations, 2-tailed significance. * Significant at 5% level. **Significant at 1% level)

Table 5.1c shows a significant positive correlation at the 5% level between the "severity global rating" and the "symptoms" subscale of the PAQOLQ. The three subscales of the PAQOLQ show significant positive correlations at the 1% level.

Table 5.1d summarises the correlations between participant, parental and provider adherence ratings.

Table 5.1d Correlations between adherence measures

	self-report	parental report
parental report	rs= 0.810 p=0.001**	
provider report	rs=0.439 p= 0.153	rs=0.322 p= 0.307

(Spearman's correlations, 2-tailed significance. **Significant at 1% level)

Table 5.1d shows a significant positive correlation at the 1% level between self-reported adherence and parental reported adherence. However, the provider perceptions of adherence are not significantly correlated with participant or parental adherence perceptions.

5.2 Aim 1: Investigation of the experience of 'having asthma' and 'taking medication'.

The results are presented according to the "sub-aims" outlined in Section 3.1.

5.21 Aim 1a: The construal of 'having asthma' and 'taking medication'.

This section summarises the grid data in relation to the construal of "having asthma" and "taking medication" for the sample population. The data is presented under the following sub-sections:

a. Constructs associated with the elements *'me with asthma symptoms'* and *'me without asthma symptoms'*.

b. Elements associated with the elements *'me with asthma symptoms'* and *'me without asthma symptoms'*.

c. Hypothesis 1: The construal of the element *'me with asthma symptoms'* is more meaningful in that it offers more implications than the element *'me without asthma symptoms'*.

5.21a Constructs associated with 'having asthma' and 'not having asthma'.

Table 5.21a presents the construct poles associated with the elements *'me with asthma symptoms'* and *'me without asthma symptoms'*. Bipolar constructs are not presented, however, the polarity of the construct is indicated in the table. Polarity refers to the participant's perception of the construct pole, and their ratings of that construct on *'ideal self'*. For example, taking the construct *"independent – dependent"*, one participant may have assigned ideal self with *"independent"*. Therefore, that participant would prefer to be *"independent"* rather than *"dependent"*. *"Independent"* therefore has a positive polarity (+). For a construct where the participant is ambivalent about which pole to assign *'ideal self'*, the polarity is not positive or negative and is designated as (+/-). Table 5.21a therefore provides a summary of how each participant construes their asthma.

Table 5.21a shows that there is a range of constructs associated with *'having asthma symptoms'* and *'not having asthma symptoms'* across the sample of participants. Using the construct categorisation system developed in Section 5.23, the constructs associated with 'having asthma' across the group are summarised into categories. Categories and frequency of constructs within each category are as follows: affect (10 constructs); autonomy (5 constructs); health status (5); social comparison (4); motivation (4); self-esteem (4); coping (3); functional status (3); achievement (2) and illness identity (1). A striking observation of these results relates to the polarity of the

Table 5.21a Summary of constructs associated with 'having asthma' and 'not having asthma' for all participants.

Participant	"Me With Asthma Symptoms"	"Me Without Asthma Symptoms"
A	feeling restricted (-) labelled with asthma (-)	independent (+) outgoing (+) satisfied (+) happy (+) healthy (+) fulfilled (+)
B	angry (-) lazy (-) feel stressed (+/-) low motivation (+/-)	feel proud of myself (+) comfortable with myself (+) calm (+) physically good at sports (+) tall, slim and popular with the ladies (+) independent (+) normal (+)
C	can't do things well (-) out of control of asthma and medication (-) unhealthy (-) lazy (-) down with myself (-) people nasty to me (-) dependent (-)	confident (+) listened to by others (+) popular (+) relaxed (+) calm (+) feel mature and old (+)
D	disappointed with myself (-) not achieving (-) shy (-)	feel I can rely on myself (+) having fun (+) able to do things (+) confident about doing things (+) same (+)
E	bored (-) uptight (-)	not worried (+) pleased with myself (+) awake and wanting to be with friends (+) normal (+)
F	poorly (-) feel sad and boring (-) ill (-)	happy (+) jealous (+/-)
G	unhealthy (-) special (-) sad (-) different (-)	joining in (+) at ease with myself (+) standing out (+) doing things I want (+)
H	feel awful (-) aggressive (-) not able to deal with my asthma (-)	happy (+) able to do things and happy about doing it (+) fine and happy (+) not scared (+) full of myself (+)
I	panicky (-) out of control (+/-) feel different (+/-)	doing what I want (+) feeling understood (+)
J	not able to do things (-) immature (-) irresponsible (-) other people making my decisions (-)	easy to breath (+) normal (+/-) calm (+) not worried (+) feel in control (+)
K	dependent (-) different (-) feel like a loser (-) unhealthy (-)	happy and content (+) people treating me like a normal person (+)
L	feeling bored (-) scared (-)	healthy (+) normal (+) sporty, active (+) happy (+)
M	abnormal (-) self-conscious (-) not safe (-) boring (-)	content/comfortable (+) unrestricted (+) accepted (+)

constructs associated with each element. Table 5.21b displays construct polarity as a percentage of the total sample of constructs for each element.

Table 5.21b Percentages of constructs assigned to polarity categories by element ('me with asthma symptoms' and 'me without asthma symptoms').

Construct Polarity	'me with asthma symptoms'	'me without asthma symptoms'
Positive	0	96
Ambivalent	9	4
Negative	91	0

There are no constructs with positive polarity associated with "having asthma". The majority (91%) are of negative polarity and a small proportion (9%) are ambivalent. In conclusion, across the sample of participants "having asthma" is construed negatively. Conversely, the majority of constructs associated with "not having asthma" are of positive polarity (96%), and a small proportion are ambivalent (4%). There are no constructs of negative polarity associated with this element. Therefore, "not having asthma" is positively construed across the sample of participants.

5.21b Elements associated with 'having asthma' and 'not having asthma'.

Table 5.21c shows the elements that are rated significantly similar to *'me with asthma symptoms'* and *'me without asthma symptoms'* across the sample. Using Table 5.21a it is therefore possible to infer how these elements are construed. Where an element is significantly associated with *'me with asthma symptoms'* it can be assumed that it is construed in the same way that *'me with asthma symptoms'* is construed. For example, from Table 5.21c it can be seen that Participant A associates *'having asthma'* with the elements *'taking medication'* and *'child with asthma'*. From Table 5.21a it can

be inferred that these elements are associated with the constructs *"feeling restricted"* and *"labelled with asthma"*.

Table 5.21c Summary of elements associated with "having asthma" and "not having asthma

Participant	"Me with asthma symptoms"	"Me without asthma symptoms"
A	F; K	A; B; G; H; I; L
B	C; H	A; F; G; I; K
C	C; F	A; B; G; H; I; J
D	F; I	A; B; G; H; I; J; K
E	C; H	A; B; G; I; J; K; L
F	H	B; G; I; L
G	C; H	A; B; G; I; J; K
H	C; H	B; G; I; J; K
I	F	A; B; G; H; I; J; K
J	C; H	A; B; G; L
K	C; G; H; K	A; B; F; I; J; L
L		A; G; H; I; J; L
M	C; H	A; F; I; J; K; L

Element Key:

A= Self
B=Ideal Self
C=Self As Was
D=Me with asthma
E=Me without asthma
F=Me taking medication
G=Me not taking Medication
H=Forget to take medication
I=As friends see me
J=As parents see me
K=Child with asthma
L=Child without asthma

The results in Table 5.21c are further summarised in Table 5.21d, which illustrates the frequency of occurrence of each element in relation to "having asthma" and "not having asthma" across the sample.

Table 5.21d Frequencies of occurrence of elements associated with 'having asthma symptoms' and 'not having asthma symptoms'

Element	"Me with asthma symptoms"	"Me without asthma symptoms"
Self	0	11
Ideal self	0	8
Self as was	8	0
Me taking medication	4	3
Me not taking medication	1	11
Forget to take medication/don't take as prescribed	8	5
As friends see me	1	12
As parents see me	0	9
Child with asthma	2	7
Child without asthma	0	7

Tables 5.21c and 5.21d indicate that there are no participants who rate themselves as *'having asthma symptoms'* and the majority of the study sample (11/13 participants) rate themselves as *'not having asthma symptoms'*. These results are addressed in detail in Section 5.22. Ratings on *'ideal self'* show a similar pattern to the ratings of *'self'*. Therefore, the majority of the sample (8/13 participants) would ideally like to be *'without asthma symptoms'*. Conversely, the majority of the sample (8/13 participants) rated *'self as was'* as similar to *'me with asthma symptoms'*. These results are consistent with the results of the semi-structured interviews, which illustrated that the majority of the sample were diagnosed with asthma during childhood, and attributed their asthma to be more severe during that period (see Appendix IV).

The majority of the sample rated the elements *'as friends see me'* and *'as parents see me'* as similar to not having asthma. The elements *'child with asthma'* and *'child without asthma'* are also rated in this fashion. In summary, the majority of the sample see themselves and feel others see them *'without asthma symptoms'*. In addition, it is

interesting to observe that the majority of the sample perceived other asthmatics to be *'without asthma symptoms'*.

It is hypothesised that the elements *'me taking medication'* and *'forget to take medication/don't take as prescribed'* reflect adherence/self-management behaviours in relation to taking asthma medicine. Specifically, *'me taking medication'* equates with adherence, while *'forget to take medication/don't take as prescribed'* reflects non-adherence. An analysis of the results reveals two distinct patterns of construing in relation to medication adherence. The results illustrate that these elements are mutually exclusive in relation to their associations with the elements *'me with asthma symptoms'* and *'me without asthma symptoms'* and therefore do not co-occur.

A 'non-adherent' profile is identified in participants who associate *'taking medication'* with having asthma and *'forgetting to take medication/don't take as prescribed'* with not having asthma. Therefore *'taking medication'* is construed negatively, while is *'forgetting to take medication/not taking medication as prescribed'* is construed positively. In contrast an adherent profile is identified in participants who associate *'forgetting to take medication/not taking medication as prescribed'* with having asthma and *'taking medication'* with not having asthma. Therefore, *'taking medication'* has positive implications, and *'forgetting to take medication/not taking medication as prescribed'* has negative implications.

5.21c Hypothesis 1: The construal of the element *'me with asthma symptoms'* is more meaningful in that it offers more implications than the element *'me without asthma symptoms'*.

The percentage sum of squares accounted for by an element has been used as a measure of meaningfulness of that element in previous studies (Drysdale, 1989). Table 5.21e displays the percentage sum of squares for the elements *'me with asthma symptoms'* and *'me without asthma symptoms'* across the sample population.

Table 5.21e Percentage sum of squares accounted for by the elements 'me with asthma symptoms' and 'me without asthma symptoms' across the sample.

Participant	'me with asthma symptoms'	'me without asthma symptoms'
A	18.72	4.29
B	12.14	1.51
C	25.30	2.98
D	9.23	2.39
E	18.68	1.94
F	15.52	8.52
G	29.05	0.71
H	13.96	7.03
I	14.97	2.68
J	12.03	6.12
K	7.87	6.55
L	22.37	4.22
M	20.16	2.63

Across all participants the element *'me with asthma symptoms'* accounts for a higher percentage sum of squares than accounted for by the element *'me without asthma symptoms'*. Therefore, "having asthma" has more implications and is more meaningful than "not having asthma". The experimental hypothesis is accepted.

5.22 Aim 1b:The investigation of the construal of the element *'self'* in relation to asthma experience and adherence behaviour.

This section summarises the grid data in relation to the construal of *'self'* for the sample population. The data is presented under the following sub-sections:

a. Summary of the elements associated with *'self'* for each participant.

b. Development of categories of *'self'* construal in relation to asthma and adherence.

c. Correlations of grid measures of "asthma identity" with measures of adherence.

d. Hypothesis 2: The construal of *'self'* in relation to having asthma is consistent with the construal of *'self'* in relation to adherence behaviour.

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5.22a Summary of elements associated with *'self'*

Table 5.22a illustrates the elements significantly associated with *'self'* across the sample population.

Table 5.22a Summary of elements associated with "self"

Participant	"Self" Elements
A	E; G; H; I; J
B	C; E; F; I; K
C	B;E;G;H;I;J;K;L
D	E; G; H; I; J; K
E	B; E; G; J; K
F	C; I; J; K
G	B; E; F; G; I; K; L
H	F; J; K
I	E; G; I; J; K; L
J	B; E; F; G; I; J; K
K	E; F; G; I; J; L
L	E; G; H; I; J
M	E; G; I; J; K; L

Element Key:

A= Self
B=Ideal Self
C=Self As Was
D=Me with asthma
E=Me without asthma
F=Me taking medication
G=Me not taking medication
H=Forget to take medication
I=As friends see me
J=As parents see me
K=Child with asthma
L=Child without asthma

5.22b The development of categories of *'self'* construal in relation to asthma and adherence.

The construal of *'self'* in relation to asthma and adherence provides the focus of this study. *'Self'* is categorised according to its associations with elements referring to asthma and adherence. To infer how each participant sees them self in relation to asthma, associations between *'self'* and *'me with asthma symptoms'* and *'child with asthma'* are used. To infer how each participant sees them self in relation to adherence, associations between *'self'* and *'me taking asthma medication'* and *'forget to take medication/don't take as prescribed'* are used.

Participants are categorised as "seeing themselves as an asthmatic" or "positive asthma identity" if they rate *'self'* similar to *'me with asthma symptoms'* and *'child with asthma'*. They are categorised as "ambivalent asthma identity" if *'self'* is rated significantly similar to one of these elements, and "negative asthma identity" if *'self'* is not rated significantly similar to either element.

Participants are categorised as "adherent" if *'self'* is rated significantly similar to *'me taking medication'* and not rated significantly similar to *'forget to take medication/don't take as prescribed'*. Participants are categorised as "ambivalent adherent" if only one of these conditions is met and "non-adherent" if neither condition is met. The self-categorisations for each participant are presented in Table 5.22b.

Table 5.22b The distribution of participants into 'asthma identity' and 'adherence' categories.

		Asthma		
		Positive	**Ambivalent**	**Negative**
Adherence Behaviour	**Positive**		**B G H J** (4 participants)	**K** (1 participant)
	Ambivalent		**E F I M** (4 participants)	
	Negative		**D** (1 participant)	**A C L** (3 participants)

The results illustrate that none of the sample have a "positive asthma identity", 9 participants were ambivalent in relation to this categorisation and 4 did not see themselves as asthmatic.

In the ambivalent asthma group, 4 participants (44% of the group) were categorised adherent; 4 participants (44%) were categorised as ambivalent in relation to adherence; and one participant was categorised as non-adherent (22%). In the non-asthmatic group, 3 participants (75% of the group) were categorised as non-adherent while one participant was categorised as adherent.

5.22c Correlations of grid measures of "asthma identity" with measures of adherence

Distances between *'self'* and *'child with asthma'*, and the anchor construct *"feel like a person with asthma"* have been extracted from the grid. It is assumed that these measures provide an indication of "identity as an asthmatic". A small distance indicates that *'self'* is associated with having asthma and therefore the participant identifies as an asthmatic. Conversely, a large distance suggests that the participant does not identify as

being asthmatic. Non-parametric correlations between these measures and self-, parental- and provider-measures of adherence are presented in Table 5.22c.

Table 5.22c Correlations between grid measures of "asthma identity" and measures of adherence.

Element/Construct Distances	Self-report adherence	Parental adherence	Provider adherence
"Self"/ "Child with asthma"	rc = -0.292 p = 0.333	rc = -0.276 p = 0.361	rc = -0.362 p = 0.247
"Self"/ "feel like a person with asthma"	rc = -0.202 p = 0.508	rc = -0.274 p = 0.365	rc = 0.170 p = 0.598

Table 5.22c shows that there are no significant correlations between grid measures of illness identity and outcome measures of adherence. Although insignificant, the direction of the correlations is consistent with the experimental hypothesis: high measures of identity as asthmatic (small distance) are associated with greater adherence (high ratings on the scale).

5.22d Hypothesis 2: The construal of *'self'* in relation to having asthma is consistent with the construal of *'self'* in relation to adherence behaviour.

The results of the self-categorisations in relation to asthma and adherence generally support the notion that adherence behaviour is related to construal as an asthmatic. Specifically, the majority of the participants who are ambivalent about their "identity as an asthmatic" categorise themselves as "adherent or ambivalent adherent" (88% of the group). Therefore, the participants who see themselves as asthmatic to some extent, engage in illness management behaviour that can be categorised as adherent. Similarly, the majority of the group who do not identify as being asthmatic are

categorised as "non-adherent" (75%). These results are consistent with the experimental hypothesis.

Within each "asthma identity" group, however, there is one result that is not consistent with the experimental hypothesis. Within the ambivalent group, one participant is categorised as "non-adherent" and within the "negative asthma identity" group, one participant is categorised as "adherent". On the basis of these results, the experimental hypothesis is rejected and the null hypothesis accepted.

The correlations between measures of "identity as an asthmatic" with outcome measures of adherence do not support the experimental hypothesis. However, the direction of the correlations is as would be predicted by the experimental hypothesis.

In conclusion, the results of the self-categorisations provide some support for Hypothesis 2 in the sense that the majority of self-adherence categorisations are consistent with the perception of the self in relation to asthma. However, the grid results of two participants are not consistent with the experimental hypothesis. The results of the correlations between grid measures of illness identity and measures of adherence do not support the experimental hypothesis. Therefore the experimental hypothesis is rejected and the null hypothesis accepted.

5.23 Investigation of the underlying themes that account for the experience of 'having asthma' and 'taking medication' in an adolescent population.

To investigate the underlying themes which account for the experience of 'having asthma' and 'taking medication', a content analysis was performed on the bipolar constructs elicited from each participant. This section provides an account of the methodology in relation to the content analysis, and outlines the final construct category system that was developed.

5.23a Content Analysis Methodology

Content analysis has been defined as 'a research technique for making replicable and valid inferences from data to their context' (Krippendorff, 1980, pg 21). Context refers to the purpose, social and cultural aspects of the document which are analysed. Content analysis has been used as a method of analysis of bipolar constructs in previous studies (Landfield, 1971). It has been employed in relation to the Asthma Grid as a method within which to aggregate the grid data and identify the underlying themes that account for the experience of having asthma and taking medication across the sample population.

The content analysis was performed in the following stages:

1. Sorting of bipolar constructs into themes/categories

All elicited bipolar constructs were sorted into general themes or categories based on the "meaning" of the construct. Anchor constructs were not included. It was necessary to view both poles of the construct, rather than one pole in isolation. This process required the inference or interpretation of the construct meaning. Provisional codes or labels were given to the data. The categories developed were exhaustive.

2. Second researcher coding

The process outlined in step 1 was repeated with a second researcher and completed independently of the first researcher.

3. Comparison of category systems

Category systems developed by researcher 1 and 2 were compared, illustrating areas of similarity and dissimilarity. Categories that demonstrated poor inter-rater reliability were discarded.

4. Development of the final category system

A single category system was developed on the basis of Step 3. Any categories that were related to each other were linked, and sub-categories developed and labelled (second-level coding).

5. Reference to individual sample grids.

Referring back to and testing out the category system on original sample grids assessed the reliability. The category system was revised further where constructs from the original sample grids could not be accounted for.

5.23b Category system for elicited construct from the Asthma Grid.

Table 5.23a illustrates the categories developed with examples of the constructs that defined the categories. Figure 5.23b illustrates the formation of sub-categories, where categories have been linked together into larger, more general categories and recoded.

Table 5.23a Summary of categories with example bipolar constructs

Coded Category	Example Bipolar Constructs
Asthma Symptoms	difficult to breath – easy to breath
Physical Health	healthy - unhealthy strong – weak fit – unfit
Vulnerability	happy – scared feel safe – unsafe feel safe – feel vulnerable
Anxiety	relaxed – uptight worried – not worried
Anger	placid – angry chilled out – angry and mad at ease with myself – angry
Excitement	having a laugh – bored excited - bored
Physical Activity	sporty, active – unfit active – bored energetic – lazy
Motivation	motivated to do things – not motivated able to do it and happy about doing it – unable and don't want to do it
Illness Coping	getting on with my life– sitting around and worrying "Why does it happen to me?" - "Just got to live with it!" forgetting I've got asthma – remembering I've got asthma not coping with my asthma - coping with it by trying to forget it in control – out of control
Illness Identity	feel normal – feel like a person with asthma see myself as a person with asthma– see myself without asthma
Illness Stigma	people see me with asthma – people see me as normal people treating me as an asthmatic– people normal with me
Social Support	people are sympathetic – unsympathetic feel cared for – feel jealous
Connectedness	popular – different accepted by others – on my own, different, left out joining in – can't keep up
Individuality	normal – perfect special – left out standing out – hiding away
Behaviour	being aggressive and nasty – being pleasant being friendly – being nasty
Independence/ Autonomy	mature and old – little and young independent – dependent other people making my decisions – making my own decisions responsible – irresponsible listened to – not listened to
Functional Ability	able to do everything – disabled asthma restricting me – not restricting me struggling to do things – able to do things
Confidence	sure of myself – not sure of myself confident – shy and retiring confident – self-conscious
Achievement	feel I'm achieving – feel I'm not achieving
Self-Esteem	feel positive about myself- feel negative about myself pleased with myself – upset with myself happy – sad proud of myself – not proud of myself

Self-Actualisation	fulfilled – still going through the challenge satisfied – frustrated reach my full potential – taking a backseat successful – failure

Figure 5.23b Content Analysis Coded Themes

Sub-Categories	Categories
Health Status	Asthma Symptoms General Health
Affect	Vulnerability Anxiety Excitement
Functional Status	Functional Ability Physical Activity
Illness Coping	
Illness Identity	Illness Identity Illness Stigma
Motivation	
Behavioural Response	
Social Support	
Social Comparison	Individuality Connectedness
Autonomy	
Achievement	
Self-Judgements	Esteem Confidence Actualisation

Figure 5.23b displays the underlying themes that account for the experience of "having asthma" and "taking medication" across the sample population. These themes are discussed with reference to models of health behaviour change and adolescent development in Section 6.1.

5.3 Aim 2: Validity of the Asthma Grid

The validity of the Asthma Grid is addressed within the following sections:

a. Hypothesis 3: Respondent Validation.
b. Triangulation of data sources.
    (i) Hypothesis 4: Comparison of the Semi-structured interview and grid results
    (ii) Hypothesis 5/6: Comparison of grid and outcome measures of asthma severity and adherence.

5.31 Hypothesis 3: Respondent Validation *"The results from the Asthma Grid are meaningful to the participant and represent the way in which they construe 'asthma' and 'taking medication'".*

Table 5.31a summarises the responses provided by participants following the feedback of the results of their grid and laddering data. These responses provide a source of data and insight into the validity of the methodology.

Table 5.31a Summary of participants' statements in relation to their grid and laddering results

Participant	Feedback Category	Additional Comments
A	accurate	"I thought the feedback was accurate, and it made me more aware of how I feel about my asthma."
B	accurate	"It was a strange thing to do, but it does show what I think about my asthma."
C	accurate	"It seemed accurate, and showed how I felt about my asthma and how I feel about myself."
D	quite accurate	"It got out my feelings about asthma and so was quite accurate."
E	accurate	No comment
F	accurate	"I was surprised that there are good things to having asthma for me, like it being exciting when I go in the ambulance."
G	accurate	"It was quite weird to do cause it made you think about things in more detail. But it does show what I feel about my asthma."
H	quite accurate	No comment
I	accurate	No comment
J	accurate	J's comments referred to the laddering exercise, "I hadn't realised that my asthma lead to all those feelings. I hadn't really looked at it like that before".
K	accurate	"It did make me look at my asthma a bit differently than before. I suppose it made me think about it more deeply."
L	accurate	"It showed that I'm not bothered about my asthma, which is true."
M	accurate	"It showed what I felt about my asthma at the time."

In summary, all the participants rated the feedback as reflecting the way they felt about their asthma and taking medication and gave no indication of ways in which the information was inaccurate. Therefore the experimental hypothesis is accepted. Interestingly, approximately half of the sample made reference to an increased awareness about issues related to their feelings of having asthma and taking medication following the interviews.

5.32 Triangulation of data sources

5.32a Hypothesis 4: ***"The results from the Asthma Grid are consistent with the results of the Semi-Structured Interview in relation to addressing issues of asthma experience and adherence."***

To assess the concordance between results of the Semi-Structured Interview (SSI) and the grid, the focus of the data from both sources has been confined to specific issues. Therefore, this analysis addresses only a proportion of the data that is available for analysis. Both data sources have been compared in relation to perceptions of *'self'* in relation to asthma experience and adherence issues as these provide the main focus of the study. The following scenario illustrates an example of a participant whose SSI and grid results collaborate in relation to asthma experience.

SSI results: the current experience of asthma is not problematic. It was more severe as a younger child.

Grid results: 'Self' is associated with 'no asthma symptoms' and 'self as was' is associated with 'asthma symptoms'.

Table 5.32a displays the frequencies of positive and negative comparisons between results of the SSI and the grid in relation to asthma experience and adherence. This data has been extracted from Appendix IV.

Table 5.32a Frequencies of positive and negative comparisons between results of the SSI and the grid in relation to asthma experience and adherence.

	Asthma	Adherence
Positive Comparison	12	11
Negative Comparison	1	2

The results of Table 5.32a show that for the majority of participants, the results of the SSI are consistent with the results of the grid in relation to addressing asthma and adherence. This provides support for the validity of grid measures in relation to assessing the experience of asthma and taking medication. Therefore the experimental hypothesis is accepted.

5.32b Hypothesis 5: ***"Measures of asthma status are significantly correlated with measures of asthma status taken from the Asthma Grid."***

Correlating grid measures of asthma severity with subjective ratings of asthma severity assesses the validity of the grid in relation to addressing perceptions of asthma severity. Four separate measures of "asthma severity" have been extracted from the grids of the sample population and include the following: distance between the elements *'self'* and *'having asthma symptoms'*; distance between *'self'* and *'not having asthma symptoms'*; and distance between the elements *'self'* and *'child with asthma'*. Table 5.32b summarises the correlations between these grid measures and subjective asthma status measures (global rating scale, PAQOLQ).

Table 5.32b Summary of correlations between grid and outcome measures of asthma severity.

Element/Construct distances	severity rating	symptoms	activities	emotions
"Self"/ "Me having asthma symptoms"	rs = 0.261 p=.390	rs = -0.204 p =.505	rs = -0.510 p=0.075	rs = -.399 p=.177
"Self"/"Me without asthma symptoms"	rs = -0.298 p =0.390	rs = -0.55 p = 0.858	rs = -0.46 p = 0.883	rs = -.182 p = 0.552
"Self"/ "Child with asthma"	rs = 0.341 p = 0.254	rs = 0.597 p = 0.031*	rs = 0.506 p = 0.078	rs = 0.404 p = 0.171

(Spearman's correlations, 2-tailed significance. * Significant at the 5%level.)

Table 5.32b shows that the grid measure defined by the distance between the elements *'self'* and *'child with asthma'* has a significant positive correlation at the 5%

level with the symptoms subscale of the PAQOLQ. The direction of this correlation supports the experimental hypothesis where a small distance between elements and a lower rating on all subjective asthma measures (refer to Section 4.2) represent "severe asthma". The measure defined by the distance between *'self'* and *'me with asthma symptoms'*, however, is not significantly correlated with any of the measures taken from the severity rating scale and the PAQOLQ. The results of Table 5.32b are consistent with those of section 5.12 in that the element *'me with asthma symptoms'* does not correlate with measures of asthma severity.

5.32c Hypothesis 6: ***"Measures of self-reported adherence indicated on a rating scale are significantly correlated with measures of self-reported adherence taken from the Asthma Grid".***

Correlating grid measures of self-adherence with outcome measures of adherence assesses the validity of the grid in relation to addressing perceptions of self-adherence. Distances between the elements *'self'* and *'me taking medication'*; and the distances between *'self'* and *'forget to take medication/don't take as prescribed'* have been extracted from the grids. A small distance between *'self'* and *'me taking medication'* indicates "good adherence". A small distance between *'self'* and *'forget medication'* indicates non-adherence. Table 5.32c summarises the correlations between these grid measures and participant self-reported adherence ratings.

Table 5.32c Summary of correlations between grid and outcome measures of adherence

	Self-reported adherence
"Self"/"Taking medication"	rs = -0.99 p = 0.746
"Self"/"Forget medication, don't take as prescribed"	rs = -0.014 p = 0.963

(Spearman's correlations, 2-tailed significance.)

Table 5.32c shows that there are here are no significant correlations between grid measures of adherence and global ratings of self-adherence. Therefore, the experimental hypothesis is rejected and the null hypothesis is accepted. Similarly, grid adherence measures are not significantly correlated with parental or provider ratings of adherence where correlations with 'self'/'taking medication' are rs = -.12, p = 0.697 and rs = -0.39, p = 0.904 respectively, and correlations with 'self'/'forget medication' are rs = 0.048, p = 0.875 and rs = -.184, p = .578.

CHAPTER 6

Discussion

The results of the study are discussed in the following sections:

- Interpretation of results
- Strengths and limitations of the study
- Clinical implications
- Suggestions for future research

6.1 Interpretation of results

The results are discussed according to the original aims set out in Section 3.1.

6.1a Aim 1: To investigate the experience of 'having asthma' and 'taking asthma medication' in an adolescent population.

The central question of the study is, "What is the experience of 'having asthma' and 'taking medication' in adolescence?" The assessment profiles, consisting of Semi-Structured Interviews (SSI), grids and laddering data (Appendix IV), give some indication of the meaning of having asthma and taking medication to each participant. Section 5.2 aggregates the data of all participants and uncovers some striking features across the group in relation to understanding the experience of having asthma and taking medication.

Table 5.21a illustrates that across the sample 'having asthma' is construed negatively while 'not having asthma' is construed positively. A finer analysis of the constructs associated with these elements reveals a range of constructions, which vary between individuals. However, the element *'me with asthma symptoms'* accounts for a larger

percentage sum of squares compared to *'me without asthma symptoms'* across the sample. The percentage sum of squares accounted for by an element has been used as a measure of the meaningfulness of that element to the participant (Drysdale, 1989). In this sample of asthmatics, *'me with asthma symptoms'* is consistently more meaningful than *'me without asthma symptoms'*. In addition, the laddering of ambivalent constructs for some of the participants indicates positive implications or "payoffs" in relation to the construal of asthma. An illustrative example can be seen in the results of the laddering process of *"feel like a person with asthma – feel like a normal person"* by Participant J (Appendix J5). The construct pole *"feel like a person with asthma"* has negative implications as it ladders to *"untrustworthy"*. However, it also has a positive implication as it ladders to *"feel special"*. Personal Construct Theory (PCT) predicts that where having a symptom is more meaningful to being symptom-free, or where it has positive implications, then that symptom can be considered as "providing a way of life" (Fransella, 1972) to which the patient adheres in the absence of a viable well-defined alternative. In total, 8 participants demonstrated this ambivalence.

In conclusion, although 'having asthma' is construed negatively across the sample, the laddering of ambivalent constructs identified some positive implications for some of the participants. Further, having asthma was consistently more meaningful than not having asthma across the group. This conclusion validates Hypothesis 1.

The way in which participants construed 'taking medication' was inferred from examining the association of the elements *'taking medication'* and *'forget to take medication/don't take as prescribed'* with having asthma and not having asthma (Table 5.21c). Two distinct patterns of construing emerged from the aggregation of the data. One group of participants construed non-adherent behaviour as being associated with having

asthma (e.g. construed negatively). A second group construed non-adherent behaviour as being associated with not having asthma (construed positively).

These results identified distinct features in relation to the construal of asthma and adherence. They did not, however, illustrate how each individual participant viewed themselves in relation to 'having asthma' and 'taking medication'. The next analysis therefore focussed on addressing how *'self'* was construed in relation to these elements.

The categorisation of *'self'* in relation to construal of asthma and adherence (Table 5.21e) revealed an interesting pattern of results as participants did not fall into distinct and clear-cut categories. For example, none of the participants associated the element *'me with asthma symptoms'* with *'self'* and therefore did not construe themselves as being symptomatic. However, a proportion of the sample did associate *'self'* with the element *'child with asthma'*. It is hypothesised that these individuals identify themselves as asthmatic even though they recognise they are not symptomatic. Perhaps this pattern of construing reflects that of an individual who is coping effectively with their asthma. These individuals were labelled "ambivalent asthma identity" as *'self'* was only associated with one of the two variables hypothesised to represent construal as being asthmatic.

A similar pattern of results emerged for self-construal in relation to medication adherence. Participants were placed in categories depending on the association between the construal of *'self'* with the elements *'taking medication'* and *'forget medication/don't take as prescribed'*. The categories were labelled positive, ambivalent and negative adherence. Participants within the 'ambivalent' group demonstrated ambivalence in relation to self-construal of adherence. For example, although *'taking medication'* was associated with *'self'*, *'forgetting to take medication/not taking as prescribed'* was also associated with *'self'*. The

development of these categories supports the results of previous studies that illustrate that adherence is not an "all-or-nothing" phenomenon. For example, an individual may be adherent to one part of a regimen but not another (Fielding and Duff, 1999).

In relation to the qualitative analysis of grid data, Hypothesis 2, *"the construal of self in relation to having asthma is consistent with the construal of self in relation to adherence"* is validated in all but 2 cases. One participant's pattern of self-construal was categorised as 'ambivalent asthmatic' and 'non-adherent'. The experimental hypothesis would predict that an 'ambivalent asthmatic' would display 'ambivalent adherent' or 'adherent behaviour'. However, this was not the case. It seems understandable that a participant categorised as 'ambivalent asthmatic' might construe themselves as non-adherent since they are unclear as to what being asthmatic means to them.

The second anomalous result is perhaps more confusing as it clearly refutes the experimental hypothesis. A pattern of 'negative asthma identity' yet 'positive adherence behaviour' is indicated on the grid. Other data (Appendix IV K) suggest that this participant was particularly concerned about the perceptions of others in relation to her asthma, as she didn't want to be seen as weak, unsuccessful or different. It seems important that her asthma, or any other vulnerabilities are hidden from other people. This will inevitably influence the way this participant construes her own asthma.

Although Hypothesis 2 was validated in the majority of cases by the qualitative data, this was not the case in the quantitative analysis. A significant limitation in the quantitative results relates to the small size of the sample population. However, as illustrated in Section 5.12d, the direction of the correlations are consistent with the experimental hypothesis.

In summary, the results suggest that self-construal of asthma is an important variable in understanding adherence. The results are consistent with previous themes which have emerged within the literature. Firstly, non-adherent behaviour has been considered a way of self-regulation (Trostle, 1988). It views patients as responsible persons who develop strategies to gain control over their situation. E.g. an individual who doesn't recognise the seriousness of their illness cannot take medication, as this would mean confirmation of the opposite. Adams et al. (1997) used the conceptual model of 'identity' to interpret the results of their qualitative study into adherence in a sample of adult asthmatics. Participants were categorised into three groups, the asthma accepters, deniers and pragmatists (individuals who didn't clearly fit into either the accepter or denier groups). They argued that adherence behaviour was directly related to the way in which participants reconciled the social identity of 'asthmatic' with self. Essentially, the commonality between the findings of this study and those of Trostle (1988) and Adams et al. (1997), is that adherence is linked and influenced by the meaning an individual makes about his/her illness and its treatment.

The content analysis of the elicited constructs revealed a system of categories/themes of constructs that accounted for the experience of asthma and taking medication in the population considered. These themes are broadly discussed with reference to previous research into chronic illness and adherence in adolescents. In an attempt to link the results to a theoretical base, the conceptual parallels between the emergent themes and models of health behaviour change and adolescent development are also illustrated. Figure 6.1a displays the conceptual links between the construct themes and cognition and social-cognition models of health behaviour change. Figure 6.1b displays the conceptual links between the construct themes and the Illness Representation Model (IRM) and Marcia's theory of adolescent identity development.

The category 'health status' incorporates asthma and health related constructs. This category links with all of the models of health behaviour change illustrated, as health orientated behaviour is dependent on an individuals' perception of the health problem. 'Affect' incorporates constructs that refer to a range of emotional states (fear, anxiety, anger, excitement). Disturbances of emotional well being, including fear, guilt, shame, depression and anxiety, are commonly observed in adolescents with chronic illnesses (Eiser, 1990; Bosley et al., 1995; Kyngas, 1999). In Kyngas's model of compliance for adolescent diabetics, fear of complications of disease management are linked directly to compliance. Such perceived vulnerability is also built into the cognition models of health behaviour change. 'Functional status' refers to constructs denoting functional ability. The functional limitations caused by a chronic illness or its treatment, have previously been implicated in determining health-orientated behaviour (LaGreca, 1990). In the IRM, the functional status of the individual is conceptualised as one aspect of the 'consequences' of the illness representation.

'Social support' incorporates a broad range of constructs relating to perceived support from others. Within chronically ill adolescents, support from both family members and peers has been linked to adherence. For example, adherence has been associated with positive family climate and open relationships between family members (Kyngas et al., 2000), parental supervision and motivation (Weissberg-Benchell, 1995). La Greca (1990b) reported that peers can be effective in providing emotional support, through acceptance of the chronic illness. It is argued that this plays a significant role in self-management behaviour. 'Motivation' has previously been implicated as an important variable for determining adherence (Baker & Stern, 1994) and is included within Kyngas' model of adherence in diabetes (1999).

'Illness coping' shows links with all of the models of health-behaviour change illustrated. Within these models, coping relies on an evaluation of the efficacy of the health behaviour in relation to effective management of the illness. 'Illness identity' incorporates constructs that relate to how participants see themselves in relation to their illness and how they feel others see them in relation to their illness (felt identity). As already discussed, illness identity has been used as a framework within which to understand adherence behaviour in an adult population. In the SCM, it is conceptualised that illness identity is related to the social context of the behavioural intention, as belief about others opinion is informed from perceptions of how others see them.

Marcia's developmental model (1966) of identity statuses has been used within this context as a framework within which to review the developmental changes that occur during adolescence. Building upon Erickson's work (1959), the achievement of identity in adolescence can be conceptualised as a series of commitment types or statuses, which are characterised by social, cognitive and emotional changes. For example, Marica outlines clear patterns of change in relation to autonomy and social interaction as individuals move through the statuses. From the Figure 6.1b, the categories of 'social comparison'; 'autonomy'; 'achievement' and 'self-judgements' are conceptually linked with this model of development.

A chronic illness poses a number of challenges to the development of the adolescent. For example, a chronic illness may mark out the adolescent as different from their peers (Kyngas et al., 2000) at a time when peer comparison and conformity is paramount. Similarly, a chronic illness may prevent the adolescent from achieving autonomy. Adolescents with diabetes and epilepsy have been found to be more socially dependent than healthy peers (Regan et al., 1993; Anderson et al., 1997). The challenges imposed by a chronic illness on development have implications for self-esteem and confidence

(incorporated into the 'self-judgements' category). Low self-esteem has been found to be more prevalent in chronic illness groups compared to healthy peers (Regan et al., 1993; Hause et al., 1993). A further study has found that in a sample of adolescents with juvenile rheumatoid arthritis, adherence was associated with higher levels of self-esteem and autonomy (Litt et al., 1982). Viewing such challenges within the context of 'identity development', it can be seen that the experience of chronic illness over adolescence may impact on the establishment of an adult identity (in relation to vocational, ideological and sexual roles).

The results of the content analysis summarise the experience of having asthma and taking medication within the sample population. The constructs elicited have been discussed with reference to previous research into chronic illness over adolescence and there are considerable parallels. Conceptual links between models of health behaviour change and adolescence have also been illustrated. The research into adherence up to this point has not resulted in the development of a model of adherence for asthmatic adolescents. In fact, there has only been one published model of adherence for this age group and that was developed in relation to diabetics (Kyngas, 1999). The lack of a satisfactory theoretical base has been attributed to the failure of many interventions, which have attempted to improve adherence in this age group. Although, these results have not been used to develop a model of adherence in adolescent asthmatics, they do illustrate issues of importance and therefore provide the foundation for beginning to understand or hypothesise about the experience of having asthma and taking medication in an adolescent population. Empirical research with larger and more diverse populations is required to address these hypotheses.

Figure 6.1a Comparison of Asthma Grid construct categories with Cognition and Social Cognition Models of Health Behaviour Change

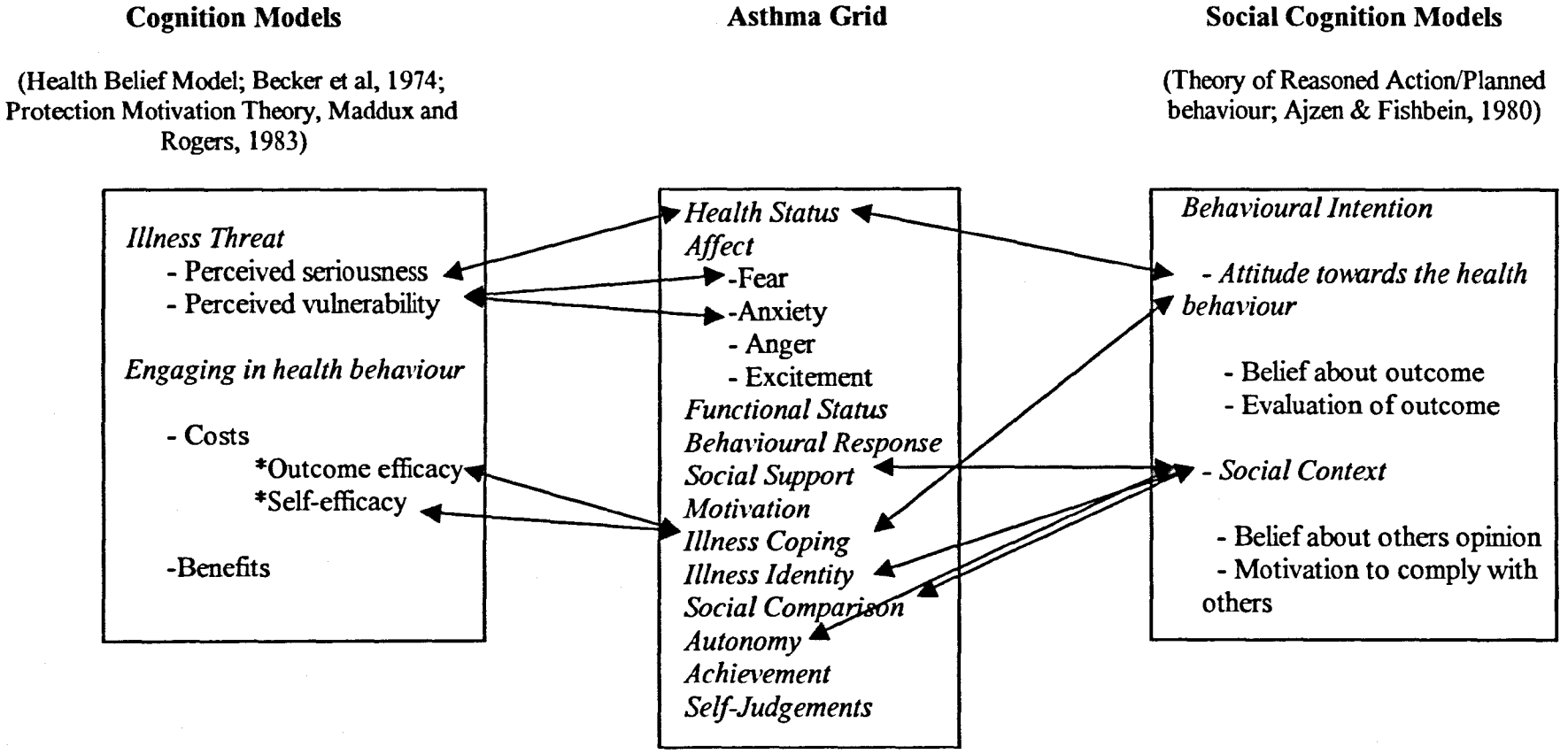
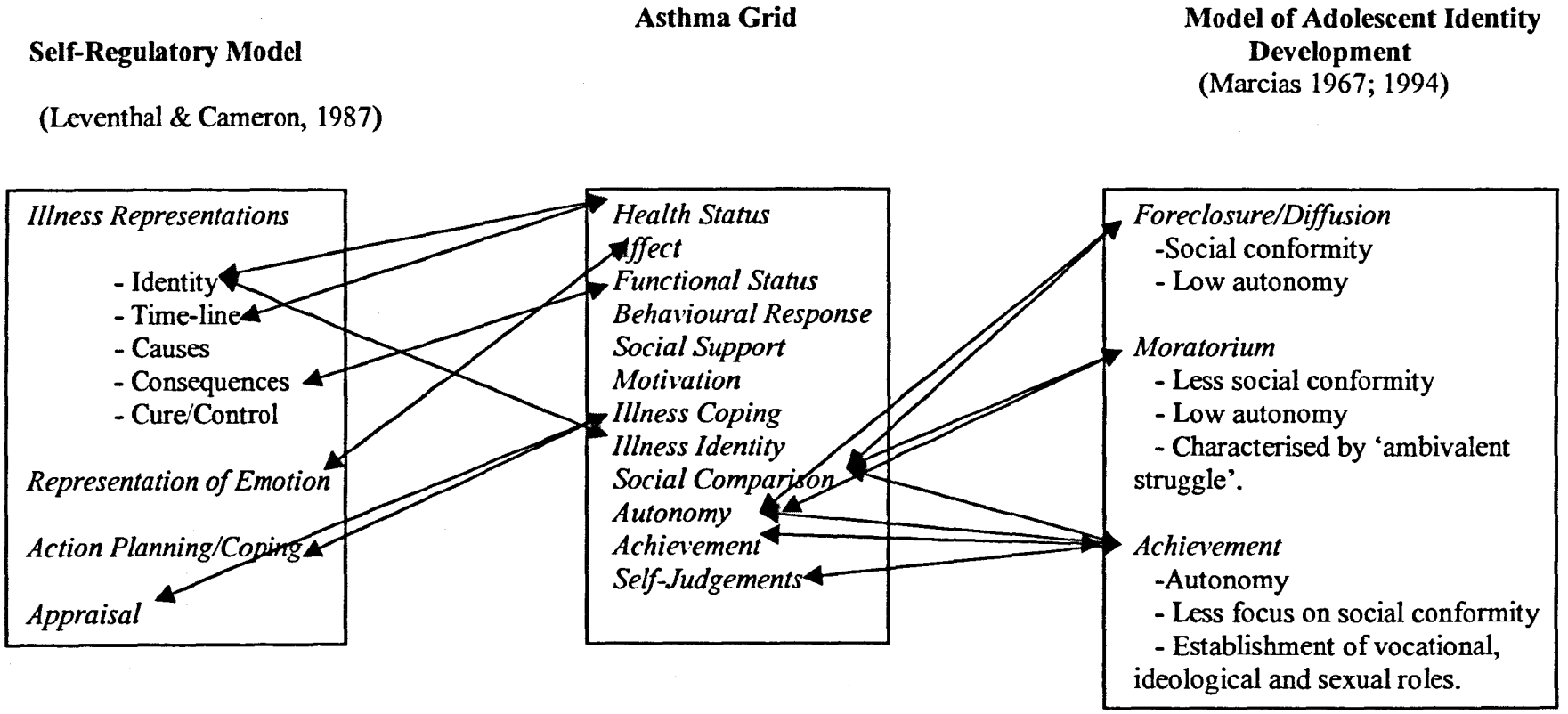


Figure 6.1b Comparison of Asthma Grid Construct Categories with the Illness Representational/Self-Regulatory Model of Illness and Marcia's Adolescent Theory of Identity Development.



The reliability of the construct system was addressed in the development of the grid by using independent researchers to develop the category system and referring back to the original grids. However, the sorting and coding of construct themes required a high level of inference about the intended meaning of constructs. This has considerable implications for the reliability and the validity of the content analysis. For example, it is conceivable that the meaning of a construct can be misinterpreted which would directly impact upon the development of the categories. Constructs were viewed in their bipolar form as a way of reducing the misinterpretation of meaning. Indeed, within all personal construct work, the issue of misinterpreting the meaning of another person's construct system is an over-riding concern and consideration. The primary researcher was arguably in a better position to infer construct meaning than the second researcher. The primary researcher carried out all of the interviews and therefore completed the content analysis with knowledge of the context in which the constructs were elicited. The second researcher categorised constructs in isolation. However, in practice this was likely to have had little impact, as the primary researcher was predominantly unaware of which constructs related to which participant.

6.1b Aim 2: Validity of the methodology

Addressing the validity of the grid methodology has been a primary concern of the study. Validity in this particular case refers to whether the grids represent participants construct systems. Do the grids reflect how participants construe having asthma and taking medication? The validity of the grid has been addressed in a variety of ways: firstly by assessing participant's perceptions of the accuracy and meaningfulness of the grids and

laddering data (respondent validation); and secondly by triangulating different sources of information about asthma perception and adherence behaviour.

'Respondent validation' outlines a process by which researchers reflect on the results of the study with the participants and refine them in light of the subject's reactions (Reason and Rowan, 1981). This process, however, has been criticised in its use as a method of validation. As Fielding and Fielding state:

"there is no reason to assume that members have privileged status as commentators on their actions....such feedback cannot be taken as direct validation or refutation of the observer's inferences. Rather such processes of so-called 'validation' should be treated as yet another source of data and insight." (1986: 43)

In summary, respondent validation used as a method of validation is criticised as it questions people's ability to reflect on their own actions. However, PCT is primarily concerned with how people make sense of events and themselves. The theory is based upon a central assumption that people's words or constructs are valid expressions of their perceptions of themselves, others and the world around them. Therefore, for the purpose of this project, which is profoundly concerned with the way that individuals make sense of their illness, respondent validation is a satisfactory method of validating the data (e.g. the grids).

Table 5.31a summarises the feedback given by participants in relation to the accuracy of the grids and laddering data. All of the participants reported that the grids did reflect how they felt about their asthma and medication. An interesting result relates to the comments of approximately half of the sample. Their reports suggest that the interview had increased their

awareness of the way they felt about their asthma and medication. This observation reflects Ravenette's comment:

"People do not appeal to their construct systems in order to act. They are their construct systems and always have been....Construct systems are built up and remain at a low level of awareness..... Our construct systems therefore are an essential part of ourselves which we, perforce, take for granted, and do not need to formulate and seldom, if ever, need to refer to." (1997, p 60).

Therefore, the results of the study are consistent with Ravenette's comments. This heightened awareness has considerable therapeutic implications for the Asthma Grid procedure and is discussed in Section 6.3.

'Triangulation' refers to the process that attempts to attain the 'truth' of a situation by combining different ways of looking at it or different findings about it. It provides a means of testing one source of information against others. If two sources give the same messages then they 'cross-validate' each other. 'Triangulation', however, has been criticised as a method of validation as it can't be assumed that data obtained from within different contexts are comparable. Unless triangulation addresses the contexts as well as the data it cannot be reliably used as a tool for validation (Fielding and Fielding, 1986).

Within the present study, triangulation has been used as a method in which to address the validity of the grids. Grid data are triangulated with results from the SSI and independent measures of asthma status and adherence. With respect to the contexts in which these sources of data were gathered, all the information was obtained directly from the participant by the principle researcher. The SSI however, was conducted with the participant and a parent

together which contrasts with how other data sources were obtained. These were gathered from each participant on his/her own. Therefore, it is important to view the triangulation of data from the SSI and the grid in light of these contextual differences.

As Table 5.32b illustrates, for the majority of the participants, grid results in relation to construal of asthma and medication are consistent with statements in the SSI. This provides some support for the validity of grid measures and elements that have been used to assess perceptions of asthma and adherence. Three participant grids, however, were inconsistent with the results of the SSI in relation to the construal of asthma and adherence. These inconsistencies might be explained by the different contexts within which both sets of data were gathered.

Another method of validation is triangulating of self-reported measures of asthma status with results from the grid (Table 5.32b). In summary, the grid measures of *'self'* and *'me with asthma symptoms'*, and *'self'* and *'me without asthma symptoms'* are not significantly correlated with any of the asthma outcome measures. The *'self'/'child with asthma'* measure is, however, significantly correlated with the 'symptoms' subscale of the PAQOLQ. In conclusion, this result suggests that the element *'child with asthma'* is a more accurate indication of participants' perception of their asthma compared to the element *'me with asthma symptoms'*. This result supports those of the qualitative analysis (Section 6.1) in which the element *'me with asthma symptoms'* did not differentiate between participants in relation to self-construal of asthma.

In interpreting these results it is important to be aware of the following issues. Firstly, the size of the sample was small and this has implications for the results. Secondly, the asthma outcome measures have limitations. The global asthma severity rating is a 'global' or

'general' rating of the participant's perception of their current asthma status. Therefore although it gives an indication of severity it is not a specific or sensitive measure. The measures of the PAQOLQ are designed to assess more specific aspects of asthma quality of life such as looking at the symptoms experienced from asthma, looking at the functional aspects of the illness and looking at the psychological aspects of their experience of asthma. Therefore, the element *'child with asthma'* seems to assess factors associated with perceptions of 'symptoms' rather than any functional or psychological correlates.

Table 5.32c displays the correlations between measures of self-reported adherence from the grid, and measures of self-reported adherence taken from a global rating scale. There are no significant correlations between any of the measures and this suggests that either one or both data sources are inaccurate. Again the size of the sample is an issue when considering these results. However, as documented within the literature (Section 1.9), measuring adherence is in itself fraught with difficulties. The research consistently suggests that people overestimate their adherence behaviour (Rand et al., 1992; Dekker et al., 1993). Reasons for this range from inaccurate recall to deliberate overestimations by participants in an attempt to tell their physician what they want to hear (Johnson, 1995). Within the current study, the non-judgemental attitude of the researcher in relation to non-adherent behaviour was emphasised in an attempt to increase the accuracy of report. Despite this, self-report measures of adherence were still likely to have been inaccurate. The adherence rating was a global measure and it was perhaps more appropriate to make it more specific and time limited.

Correlations between participant, parent and provider perceptions of adherence (Table 5.1d) indicate a discrepancy in the reports and/or perceptions of adherence by patients and their providers. Participant reports show significant correlations with parental report, however, neither correlate with provider reports. It is commonly recognised that provider

estimates of adherence are inaccurate. In addition, previous research has indicated that participants and their parents collude in relation to reporting about adherence (Bender et al, 1998). Within this study, however, the lack of a rigorous and objective measure of adherence makes it difficult to draw any firm conclusions about these results. This is considered a significant limitation to the study and is discussed further in Section 6.2.

6.2 Strengths and limitations of the study

The main strength of this study lies with the use of personal construct methodology. Understanding the experience of having asthma and taking medication in adolescence was the central aim of the study. The chosen methodology, which is based in phenomenology, is well equipped to address this central aim. It investigated the participant's perceptions, thoughts, and feelings (constructions) of their illness from within their own context and didn't attempt to steer their reports by presupposing issues of importance. Within the literature, there is a considerable gap in relation to understanding adherence behaviour in this population despite the recognition that adherence issues are of particular significance over this developmental stage. Therefore, this study has worked towards providing some insight into the experience of having asthma and taking medication during adolescence.

It can also be argued that there are particular benefits of using personal construct methodology over other methods in relation to assessing adherence. The grid procedure is a sensitive and non-judgemental method by which to gain a glimpse of how people view their world. Such non-judgemental methods are likely to yield more accurate results from individuals in relation to reports about adherence behaviour.

A significant limitation of the study, however, relates to the implicit nature of the principal researcher's influence in planning, carrying out and interpreting the project. Although, as already stated, PCT investigated participant's experiences of asthma and medication from within their own context, the research did not take place in a vacuum. The principal researchers' experiences, thoughts, beliefs and motivations influenced the research process. For example, the principal researcher directly influenced the elicitation of constructs by selecting a list of elements rather than eliciting elements directly from each participant. The principal researchers own construct system is likely to have influenced the interpretation of the meanings of bipolar constructs for allocation into themes within the content analysis. Processes of researcher reflexivity are an integral and explicit component of qualitative research methodologies. This process of researcher reflexivity was not made explicit within this project and is therefore a considerable limitation. The inclusion of a research diary could have been one way in which to address and document the influence of the researcher on the research process.

The study addressed issues of reliability although it didn't assess it. Reliability of the repertory grid is concerned with whether the procedure is able to reveal stable features of a person's style of construing. Although flexibility is considered an asset of the technique, some caution must be taken to ensure that similar procedures are used with each participant. Reliability was addressed, for example, by standardising the order and content of procedures. For example, a standard procedure was outlined for eliciting, recording, clarifying and laddering constructs and also for providing feedback.

The comparison of grids developed at two separate points in time would have addressed the test-retest reliability of the procedure. Although PCT predicts that grids will change from one assessment to the next, as construct systems are constantly evolving (the experience

corollary), a participant's *core* construing would be expected to remain relatively stable, and this could be used to provide an indication of reliability. Inter-rater reliability refers to the stability of the grid procedure as used by different interviewers. Comparison of grids developed by two independent researchers would give another indication of reliability.

A further limitation of the study relates to the assessment of asthma status and adherence. Subjective measures of asthma functional status were obtained within the project, however information about actual disease status was not gathered. Objective clinical measures of disease status, such as peak flow readings, would have provided another dimension. It was assumed that type and frequency of prescribed medication could be used as an indication of asthma status. However, this may have borne little relation to actual disease variables. Firstly, symptoms of asthma wax and wane over time and as indicated in the results of the SSI for one participant (Appendix IV, G1), adherence behaviour (and constructions) may vary considerably depending on the illness status. Secondly, participants were sampled across different general practice surgeries. With the absence of a clinical gold standard for asthma treatment and assessment it seems unlikely that an accurate indication of illness status can be gained through classification by medication.

As already discussed, the measures of adherence obtained were far from adequate. The measures gave some indication as to perceptions of adherence behaviour; however, it is likely that these measures could have been more accurate if they were more specific and time-limited. Perhaps the use of a participant diary would have been an insightful method. Further, the study focussed on perceptions of adherence, it did not provide measures of actual adherence behaviour and therefore did not address the predictive validity of the grid. Understanding reasons behind adherence was the central focus of this study, not documenting the extent to which participants were or were not adherent. However, addressing the extent to

which grids can predict adherence behaviour is an important issue and may provide a focus for future research (Section 6.4).

Finally, the size of the sample was very small and should be considered when interpreting the results. A specific consideration relates to the general characteristics of the sample, and of whether it is representative of a general practice asthmatic adolescent population. Firstly, the sample consisted of only two males and therefore the results are considered more representative of a female population. Secondly, viewing the demographic results suggests that the sample consists of a group of relatively mild/moderate asthmatics, or a group of individuals who were not experiencing difficulties with their asthma at the time of the interview. The data also suggests that the sample were a group of 'good' adherers. Illness control has previously been used as an indicator of adherence (Van Ganse, 1997). None of the group had been admitted to hospital over the past two years for acute asthmatic episodes. Further, it is logical to assume that it is mostly 'good adherers' and motivated individuals who are likely to volunteer for studies such as this. The results should be interpreted in light of these issues and caution exercised in relation to the generalisation of these results to other populations.

6.3 Clinical implications

The results of this study tentatively suggest a relationship between constructions of self in relation to illness and constructions of the self in relation to illness management. This finding has considerable clinical implications as it suggests that illness management behaviour is consistent with the way people see themselves and their illness. The results also suggest that the way people view themselves in relation to their illness and illness management is complex. Self-perceptions of adherence behaviour are not defined by distinct

categories. It is likely that people's perceptions are influenced by a multitude of factors. In relation to adolescents, it seems that having asthma is tied up to other issues of development.

The use of personal construct methodology to address adherence has considerable clinical and therapeutic implications for working with patients across illnesses and across the life-span. Within this study, the Asthma Grid methodology was developed as an assessment tool to address participants' experience of having asthma and taking medication. As can be seen from the results, the grid procedure elicited a wealth of information about participants' constructions of their illness and the relationship of that to their constructions of adherence behaviour. With an understanding of these constructions, a clinician is able to address and work with the patient. Such a model of doctor-patient interaction works towards Marinker's (1997) model of concordance where the patients' and doctors' health beliefs are viewed as being equally important.

The flexibility of the procedure makes it malleable to a diverse range of clinical environments. The procedure could be simplified, for example using fewer elements and eliciting fewer constructs. Therefore, it presents as a cost effective and flexible tool for finding out about how people make sense of their illness and related behaviour. In addition, it provides a way forward for therapeutic interaction.

6.4 Recommendations for future research

This study reveals some interesting results about illness and self-management behaviour constructions in adolescence and their relationship. However, the small sample size and limitations in relation to the accurate assessment of adherence behaviour make it very difficult to draw any firm conclusions from the results. An area for future research

relates to addressing some of these limitations, specifically, using the methodology over a larger and more diverse population (accounting for gender and addressing participants who are considered less adherent). It would also be interesting to assess individuals across illnesses.

A second suggestion for future research relates to assessing the potential therapeutic implications of the procedure. Participating in the assessment invites an individual to think about the way they make sense of things or "stock take" (Ravenette, 1997). Out of this an individual may either develop alternative ways of making sense of their world and experiences, or they may become aware of the construct system that underlies their present way of making sense of their world. While these processes are not directly therapeutic, they may encourage change in construing and behaviour. Therefore, an interesting focus for future research lies in a longitudinal investigation of change in construing illness and illness management behaviours following administration of the grid, with an emphasis on monitoring actual changes in adherence behaviour.

Another area of potential research lies in how providers construe their patients. The role of doctor and patient relational factors in adherence is becoming recognised as increasingly important. It would be interesting to investigate provider perceptions of the reasons behind their patient's non-adherence. Comparison of grids with those of their patients may reveal some dramatic anomalies.

A final suggestion for future research relates to development of a tool based on personal construct methodology which is easy to use by clinicians working across different patient groups. The development of such a tool may have considerable implications for the day-to-day work of health professionals who encounter problems of adherence in relation to their patients.

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APPENDIX I

List of element triads

1. Me having asthma symptoms	Me not having asthma symptoms	Me taking asthma medication
2. Me having asthma symptoms	Child with asthma	Child without asthma
3. Me as I am	Me as my friends see me	Me as my parents see me
4. Me having asthma symptoms	Forget to take medication	Child with asthma
5. Me as I am now	Me as I used to be	Me as my parents see me
6. Me as I used to be	Me not having asthma symptoms	Child with asthma
7. Me as I would like to be	Me as my friends see me	Me as my parents see me
8. Me as I am now	Me taking asthma medication	Forget to take asthma medication
9. Me as I am now	Me having asthma symptoms	Me not having asthma symptoms
10. Me as I used to be	Forget to take asthma medication	Child with asthma
11. Me as I am now	As I used to be	As my friends see me
12. Me as I am now	Me as I used to be	Me as I would like to be

APPENDIX II

An example of a completed Asthma Grid

	Construct (1) 7 6 5 4 3 2 1 Contrast(2)		Me as I am	Me as I want to be	Me as I used to be	Me with asthma	Me without asthma	Me taking asthma medication	Forget medication	Me not taking asthma medication	As friends see me	As parents see me	Child without asthma	Child with asthma
1	angry/mad	chilled out	3	2	3	5	3	5	3	3	4	4	4	5
2	feel normal	feel different	5	6	4	3	6	4	6	6	6	5	4	5
3	treated as normal	labelled with asthma	5	7	5	3	6	3	5	6	6	5	3	6
4	satisfied	frustrated	6	6	5	3	5	2	6	6	6	4	6	6
5	asthma restricting me	feel unrestricted	4	1	4	5	2	3	3	4	2	4	5	6
6	outgoing	restrained	6	7	4	3	6	3	7	5	7	5	7	4
7	having people about me	lonely	7	5	6	7	7	6	7	7	7	7	5	4
8	ignore asthma	take medication	3	7	6	2	6	2	5	6	6	4	7	2
9	independent	mollycoddled	6	7	3	3	6	2	6	5	7	5	6	4
10	happy	sad	6	7	5	3	6	3	6	5	6	4	5	5
11	healthy	weak	4	6	3	3	6	5	5	5	6	4	5	3
12	active	bored	6	5	5	4	6	6	6	6	7	6	6	4

APPENDIX III

Participant feedback evaluation form

This form relates to "what you think about" the written feedback. Please complete the following questions and return to me in the stamped addressed envelope provided.

(1) In your opinion, is the information in the feedback letter accurate? Does it show what you feel about your asthma and taking medication?

Very Accurate (1) (2) (3) (4) (5) Not at all accurate

(2) If there are inaccuracies, please write down what they are.

(3) Have the interviews made you think differently about your asthma in any way?

(4) Have you got any further comments relating to the interviews or the results?

APPENDIX IV

Assessment Profiles

The following information is presented for each participant:

1. Demographic data

The following information is presented: gender; age; age at diagnosis; current reliever and preventer medication.

2. Semi-structured interview (SSI)

Statements/excerpts from the interviews that refer to current and past asthma and medication experience are listed. The data is presented under the categories 'asthma quotes/information' and 'medication quotes/information'. There has been no attempt to categorize this data further.

3. Asthma Grid

- Grid Diagram: visual representation of results from the principle components analysis (PCA) showing the loadings of constructs and elements onto the first two components.
- Element Key: presents a list of all the elements for use when interpreting the grids.
- Table: construct loadings onto the first two components. All the loadings onto the first component are displayed in the table as this provides a full list of the bipolar constructs, which can be used when interpreting the grid. Construct percentage variances are also displayed. This has previously been used as a

measure of construct superordinacy (Bannister & Salmon, 1967, see Section 4.31).

4. Grid Data

The following are discussed with reference to the grid:

- Structural properties of the grid.
- Construct loadings onto the x- and y-axes.
- Element percentage variance.
- Element loadings onto the x- and y- axes.

5. Laddering Data

Laddered constructs are presented in this section.

6. Comparison of data sources: Semi-structured interview; Asthma Grid; Laddering.

These three sets of data are compared with each other, attending to significant areas of cross-validation and invalidation.

Participant A:

A.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	16	5 years	Salbutamol	Beclomethasone dipropionate

A.2 Semi-structured interview

(i) Asthma information/quotes

- "My asthma has got much worse over the past two years than it was when I was younger."
- "I try to ignore it and don't give it much attention, but it does bother me when I can't do the things I want to. I'm a really active person and get bored and frustrated when I can't do all my sports and go out with friends."
- 'A' referred to possible psychological factors for explaining the onset of her asthma:

" I first got my asthma when I was 5 years old, on my first day at school. My Mum thinks I got it because of being stressed, but I remember being really happy at school".

"My Mum thinks I get my asthma when I've been doing too much and am stressed out. Maybe she's right, I don't know."

(ii) Medication information/quotes

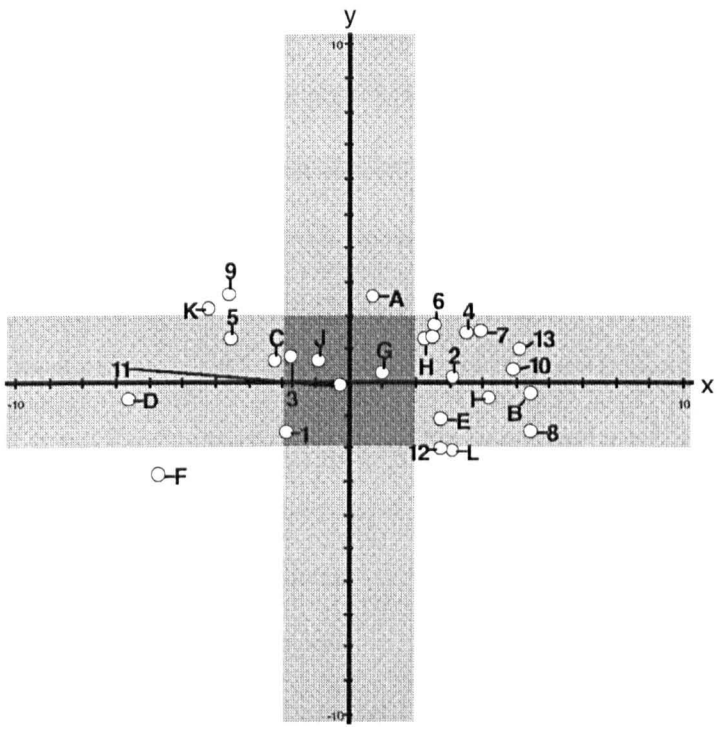
- "I really don't like taking medication, especially the preventer. I just don't want to be dependent on it."
- "I will always take my reliever when I need it but I will only take my preventer when my asthma is really bad."

A.4 Grid data

(i) Structural properties

- The grid shows a predominantly one-dimensional structure in which constructs and elements cluster around the x-axis. Components 1 accounts for 66.88% while Component 2 accounts for 10.81% of the variance. This grid reflects a tightly organised construct system.

A.3 Asthma Grid



x-Axis: Component 1 (66.88%)
y-Axis: Component 2 (10.81%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative values	Positive values
1	8	5.5	16.57	take medication	ignore asthma
	13	5.1	11.65	mollycoddled	independent
	10	4.9	10.36	restrained	outgoing
	7	4.0	8.12	frustrated	satisfied
	9	-3.6	8.41	feeling restricted	not feeling restricted
	4	3.5	6.57	sad	happy
	5	-3.5	6.57	labelled with asthma	treated like I don't have asthma
	2	3.1	4.66	different	normal
	12	2.8	5.83	weak	healthy
	6	2.6	4.66	disappointed	fulfilled
	14	2.5	4.24	sad	special
	1	-1.9	4.14	angry	chilled out
	3	-1.7	3.46	bored	active
	11	-0.3	4.76	lonely	having people about me
2	9	2.6	8.41	not feeling restricted	feeling restricted
	12	-2.1	5.83	healthy	weak
	6	1.7	4.66	disappointed	fulfilled

(ii) Construct loadings onto Component 1

- The construct "taking my medication – ignoring my asthma" accounts for the highest percentage variance (16.6 %) and loads significantly onto the x-axis so that the positive pole of the x-axis represents the construct pole "ignoring my asthma".
- The negative pole of the x-axis is elaborated in terms of the construct "feeling restricted" which is significantly correlated with "labelled with asthma" ($r = 0.83$).
- The following constructs have significant correlations with "ignoring my asthma" and therefore further elaborate the positive pole of the x-axis: "normal (different)" ($r = 0.71$); "satisfied" ($r = 0.76$); "outgoing" ($r = 0.72$); "independent" ($r = 0.64$); and "healthy" ($r = 0.59$).

(iii) Construct loadings onto Component 2

- The construct "not feeling restricted – feeling restricted" loads onto the y-axis where "feeling restricted" represents the positive pole.

(iv) Element percentage sum of squares

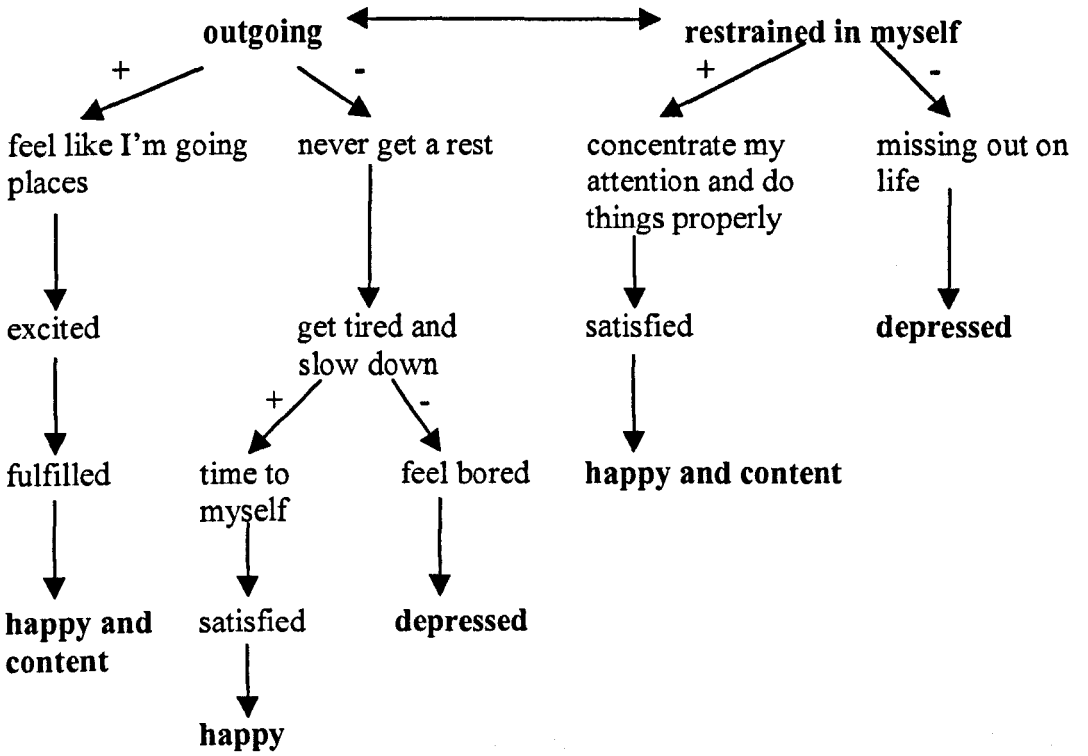
- "Me with asthma" accounts for a larger percentage variance (18.72%) compared to "me without asthma" (4.29%) or "self' (3.96%).

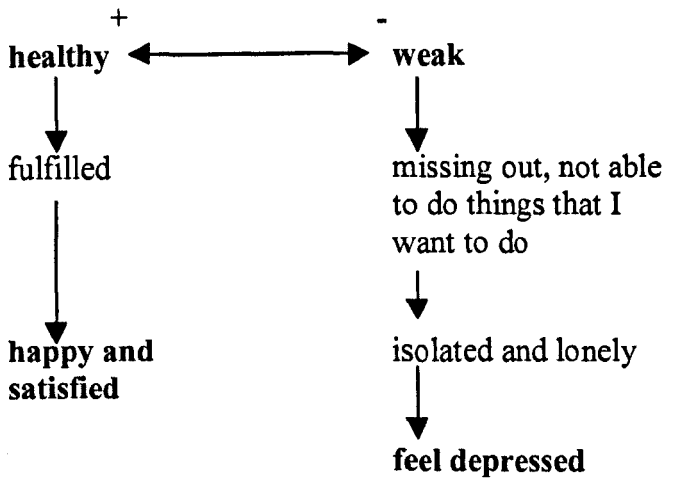
(v) Element interrelationships

- "Self" is not significantly associated with "self as was" (distance = 0.67) or "ideal self" (distance = 1.09).
- "Self" is rated as significantly similar to "me without asthma" (distance = 0.69). There is no significant association with "me with asthma".
- "Self" is rated significantly similar to "forget to take medication/not taking medication when I should" (distance = 0.41) and significantly dissimilar to "me taking asthma medication" (distance = 1.25).
- "Ideal self" is rated as significantly similar to "me without asthma" (distance = 0.57); "as friends see me" (distance = 0.58); and "child without asthma" (distance = 0.65). These elements load onto the positive pole of the x-axis and negative pole of the y-axis which are defined by "ignoring my asthma" and "not feeling restricted" respectively.

A.5 Laddering

The construct "outgoing – restrained in myself" was laddered as it was identified as an ambivalent construct. "Healthy – weak" was also laddered.





A.6 Comparison of data sources: SSI; Asthma Grid; Laddering

- Elicited constructs relate to A's statements given in the SSI, specifically in relation to "ignoring asthma" and "feeling restricted by asthma".
- The grid indicates that A does not see herself as a person with asthma. She has rated herself as similar to the element "me without asthma" and dissimilar to "me with asthma" and "child with asthma". Similarly, she did not rate herself as she was in the past as similar to "me with asthma". These results do not reflect her comments given in the SSI, which implied that her asthma has been more severe recently.
- Results from the SSI suggest that A does not consistently adhere to her prescribed medication regimen. The grid supports and further elaborates upon this. Firstly, it shows that "self" is rated as very similar to "forgetting to take medication/not taking as prescribed". Further, the construct "taking medication – ignoring asthma" loads most heavily onto the x-axis. The pole "ignoring asthma" is positively correlated with constructs such as "independent" and feeling "happy and satisfied". Therefore "ignoring asthma" has positive implications for A, where "taking medication" has negative implications, thus explaining her adherence behaviour.
- "Outgoing – restricted in myself" and "healthy – unhealthy" both ladder down to the poles "happy and satisfied" and "depressed" and this indicates that these may be core constructs. These ladders bring greater meaning to the constructs that are seen in the grid.

Participant B:

B.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
male	16	3 years	Salbutamol	Beclamethasone dipropionate

B.2 Semi-Structured Interview (SSI)

(i) Asthma information/quotes

- "I just get on with my asthma at the moment. I don't think it's really that bad."
- My asthma used to be bad when I was younger, when I was about 7, 8, 9 years old. I used to miss school quite a bit."
- Now I get my asthma when I do exercise, so I'm not that good at sports.

(ii) Medication information/quotes

- "It is normal to take my medication. I don't even think about it".

4. Grid data

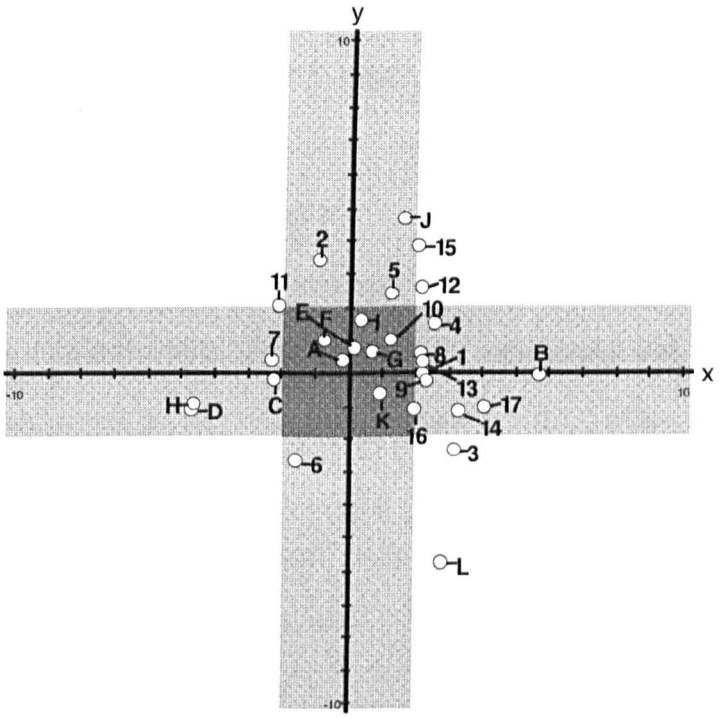
(i) Structural properties

- The grid shows a clear two dimensional structure, where Components 1 and 2 account for 44.76% and 29.98% of the variance respectively. This grid does not reflect a tightly organised construct system.

(ii) Construct loadings onto Component 1

- The construct "feel like a person with asthma –feel healthy" accounts for the highest percentage variance (10 %) and loads significantly onto the x-axis so that the positive pole of the x-axis represents the construct pole "feel healthy".
- The negative pole of the x-axis is elaborated in terms of the construct "angry" which is significantly correlated with "feel lazy" ($r = 0.59$).
- The following constructs have significant correlations with "healthy" and therefore

B.3 Asthma Grid



x-Axis: Component 1 (44.76%)
y-Axis: Component 2 (29.98%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative values	Positive values
1	17	4.1	10.00	feel like a person with asthma	healthy
	14	3.3	7.74	unhealthy	healthy
	3	3.2	9.96	rubbish at sports	physically good at sports
	4	2.6	5.20	average at everything	feel I've achieved
	9	2.3	4.29	squat and round	tall, slim and popular with the ladies
	7	-2.3	4.88	angry	placid
	13	2.2	3.17	different	normal
	1	2.2	5.71	distressed and wheezy	normal
	12	2.2	6.15	worried	relaxed and at ease
	8	2.2	3.29	frustrated	calm
	11	-2.1	5.20	lazy	energetic
	15	2.0	9.96	average	special
	16	2.0	3.29	reliant upon others	independent
	6	-1.6	6.15	stressed	layed back
	5	1.3	5.20	not proud of myself	proud of myself
	10	1.3	1.75	hating what I am	comfortable with myself
	2	-0.9	8.06	low motivation	feeling motivated
2	15	3.8	9.96	average	special
	2	3.4	8.06	feeling motivated	low motivation

further elaborate the positive pole of the x-axis: "normal (different)" (r = 0.76); "normal (distressed and wheezy)" (r = 0.69); "tall slim and popular with the ladies" (r = 0.73); "independent" (r = 0.71); "calm" (r = 0.62); "physically good at sports" (r = 0.69); "healthy" (r = 0.73).

(iii) Construct loadings onto Component 2

- The construct "feel special – feel average" loads onto the y-axis where "feel special" represents the positive pole. "Special" correlates significantly with "feel comfortable with myself" (r = 0.78) and "relaxed and at ease" (r = 0.83) which further elaborate the positive pole of the y-axis.
- The construct "stressed – layed back" loads onto the negative pole of the y-axis, where "stressed" represents the negative pole.

(iv) Element percentage sum of squares

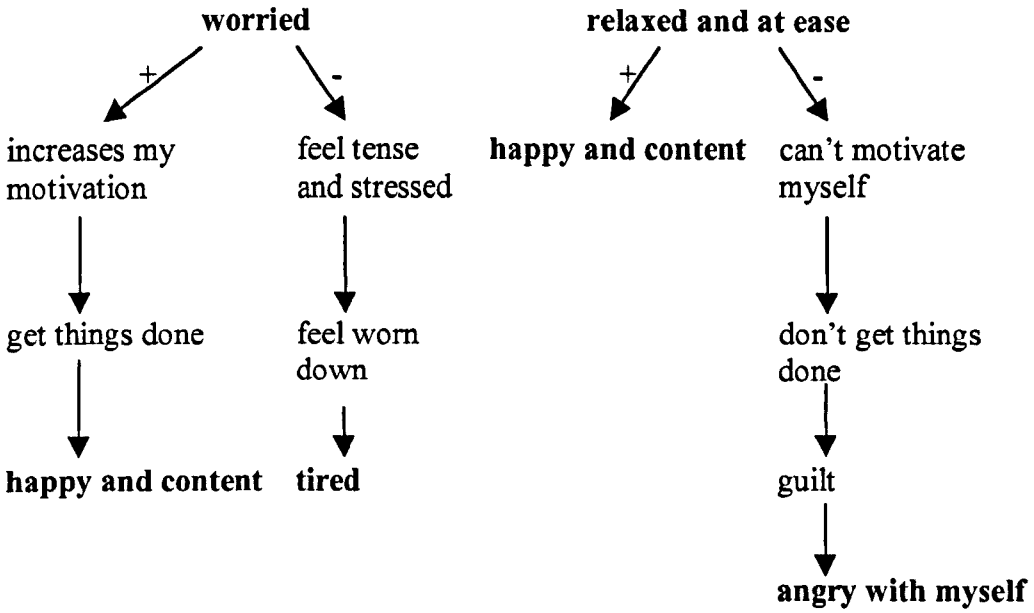
- "Me with asthma" accounts for a larger percentage variance (12.14%) compared to "me without asthma" (1.51%) or "self" (1.11%).

(v) Element interrelationships

- Self is rated as significantly similar to "self as was" (distance = 0.67) but is not significantly associated with "ideal self" (distance = 1.09).
- "Self" is rated as significantly similar to "me without asthma" (distance = 0.23). There is no significant association with "me with asthma".
- "Self" is rated significantly similar to "me taking asthma medication" (distance = 0.35). It is not rated significantly dissimilar to "forget to take medication/not taking medication as prescribed" (distance = 0.87).
- "Me with asthma" is rated significantly similar to "forget to take medication/not taking medication as prescribed" (distance = 0.4) and "self as was" (distance = 0.74). These elements load onto the negative pole of the x- and y-axes defined by "feel like a person with asthma" and "stressed" respectively.

5. Laddering

The construct "worried – relaxed and at ease" was laddered as it was identified as an ambivalent construct.



B.6 Comparison of data sources: SSI; Asthma Grid; Laddering

- B's statements from the SSI indicated that his asthma wasn't problematic at the time of the interview. The results from the grid support this as it shows that B has rated himself as similar to "me without asthma symptoms". In addition, the grid shows that "self as was" is rated as similar to " having asthma". This corroborates with B's initial statements implying that his asthma was more problematic at a younger age.
- Results from the SSI suggest that B finds it "normal" to take medication. The grid supports and further elaborates this area of construing. Firstly, it shows that "self" is rated as very similar to "taking medication" and dissimilar to "forgetting to take medication". Therefore B perceives himself as a good adherer. Further, the mechanisms behind such "adherence" behaviour can be hypothesised from the grid. Specifically, "forgetting to take medication" is associated with "having asthma" which is significantly dissimilar to how he would like to be (ideal self).
- The laddering of "worried – relaxed and at ease" elaborates upon the constructs which load onto the y-axis. Specifically it illustrates an area of ambiguity or conflict within B's construct system and explains the position of "ideal self" on Component 2.

Participant C:

C.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	15	5 years	Salbutamol	Fluticasone propionate

C.2 Semi-Structured Interview

(i) Asthma Information/Quotes

- "My asthma has calmed down over the past year."
- "My asthma was much worse when I was 8/9 years old. I was referred to a clinic at the hospital."
- "My asthma used to really annoy and embarrass me. It doesn't bother me so much anymore."
- C's mother, who also has asthma, commented *"C takes after me, we're both the weak ones who get ill in our family".*

(ii) Medication information/quotes

- "I feel fine about taking my current medication, I've got used to it now!"
- " I feel I understand about my asthma more, and that's why I take my medication better. When I was younger I didn't really understand that I have to take my preventer to keep symptoms down. I just used to think the doctors didn't understand me, they didn't understand how difficult it is to take all those medications, and I didn't think they would listen to me. So I used to think 'why should I listen to them?"

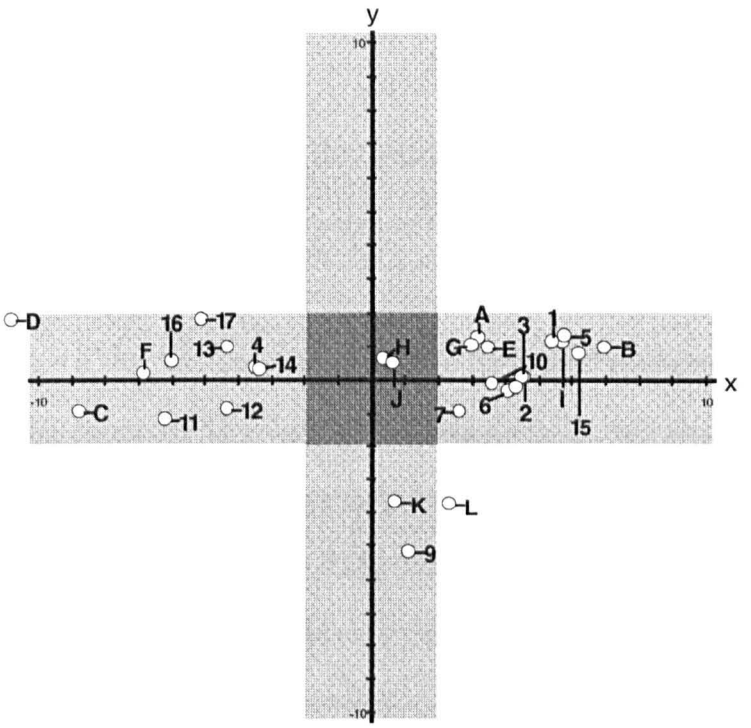
4. Grid data

(i) Structural properties

- The grid shows a predominantly one-dimensional structure, where Components 1 and 2 account for 72.42% and 7.81% of the variance respectively. This grid reflects a tightly organised construct system.

(ii) Construct loadings onto Component 1

C.3 Asthma Grid



x-Axis: Component 1 (72.42%)
y-Axis: Component 2 (7.81%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative values	Positive values
1	15	6.2	9.37	feel like a person with asthma	feel like a person without asthma
	11	-6.2	8.72	in control of asthma and medication	out of control of asthma
	16	-6.1	7.72	can do things well	can't do things very well
	5	5.8	8.32	shy	confident
	1	5.4	6.84	embarrassed	confident
	17	-5.1	6.32	healthy	unhealthy
	2	4.6	6.97	stressed	relaxed
	3	4.5	5.13	geeky and outcast	popular
	8	4.4	4.58	weak	strong
	13	-4.4	5.93	active	lazy
	12	-4.3	4.58	fine with myself	down with myself
	6	4.1	6.44	panicky	calm
	10	3.6	3.78	not listened to by others	listened to by others
	4	-3.5	3.25	people kind to me	people nasty to me
	14	-3.3	3.79	independent	dependent
	7	2.6	2.13	little and young	mature and old
	9	1.2	6.13	different from others	the same as others
2	9	-5.2	6.13	different from others	the same as others
	17	1.8	6.32	healthy	unhealthy
	5	1.3	8.32	shy	confident

The construct "feel like a person without asthma – feel like a person with asthma" accounts for the highest percentage variance (9.37%) and loads significantly onto the x-axis so that the positive pole of the x-axis represents the construct pole "feel like a person without asthma".

- The negative pole of the x-axis is elaborated in terms of the construct "out of control of asthma and medication" which is significantly correlated with "down with myself" (r = 0.69); "unhealthy" (r = 0.76); "can't do things well" (r = 0.88); and "people nasty to me" (r = 0.77)".
- The following constructs have significant correlations with "feel like a person without asthma" and therefore further elaborate the positive pole of the x-axis: "confident (shy)" (r = 0.77); "confident (embarrassed)" (r = 0.88); "relaxed" (r = 0.58); "strong" (r = 0.77); "calm" (r = 0.67); "popular" (r = 0.92); "listened to by others" (r = 0.69); "feel mature and old" (r = 0.66).

(iii) Construct loadings onto Component 2

- The construct "same as others – different from others" loads onto the y-axis where "different from others" represents the negative pole.

(iv) Element percentage sum of squares

- "Me with asthma" accounts for a larger percentage variance (25.36%) compared to "me without asthma" (2.98%) or "self" (3.48%).

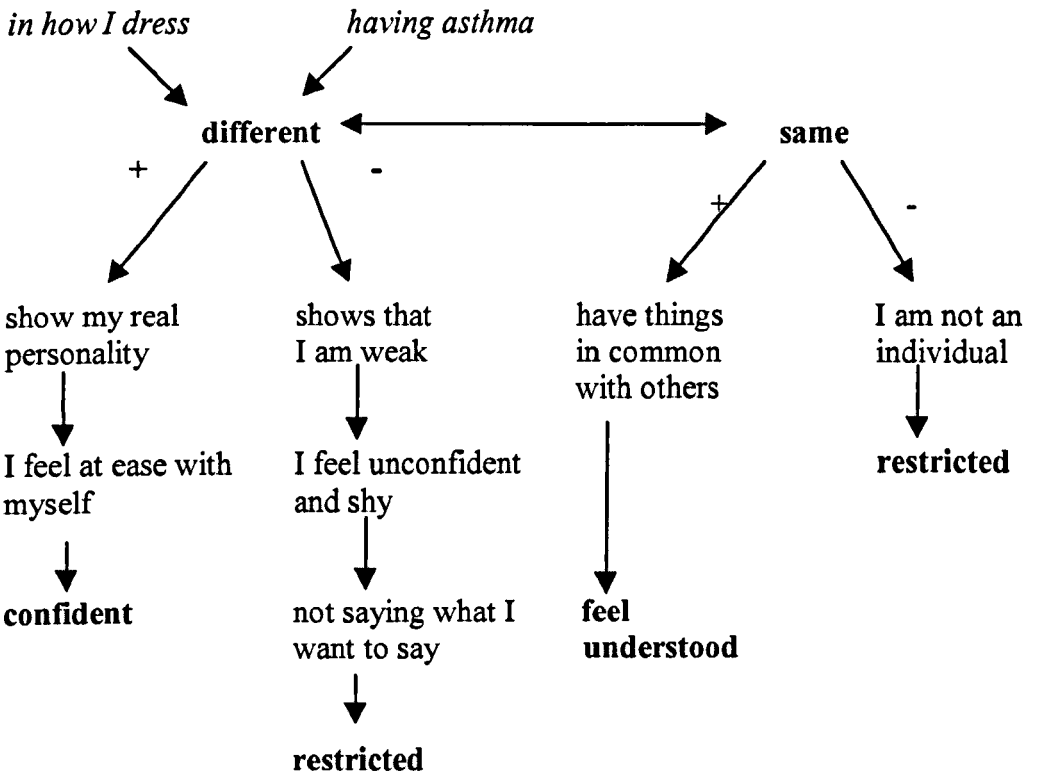
(v) Element interrelationships

- "Self" is rated as significantly similar to "ideal self" (distance = 0.6) and significantly dissimilar to "self as was" (distance = 1.33).
- "Self" is rated as significantly similar to "me without asthma" (distance = 0.23) and significant dissimilar to "me with asthma" (distance = 1.53). It is also rated as significantly similar to "child without asthma" (distance = 0.68).
- "Self" is rated significantly similar to "forget to take asthma medication/not taking medication as prescribed" (distance = 0.67).
- "Self as was" is rated significantly similar to "me taking asthma medication" (distance = 0.68) and "me with asthma" (distance = 0.06). These elements load onto the negative pole of the x-axis defined by "feel like a person with asthma".

• "Forget to take asthma medication/not taking medication as prescribed" is significantly correlated with "as parents see me"(distance = 0.62).

C.5 Laddering

"Different – same" was laddered as this was identified as an ambivalent construct.



C.6 Comparison of data sources: SSI; Asthma Grid; Laddering

• C's statements from the SSI indicated that her asthma wasn't problematic at the time of the interview. The results from the grid support this as it shows that C has rated herself as similar to "me without asthma" and "child without asthma". In addition, the grid shows that "self as was" is rated as similar to " having asthma". This corroborates with C's initial statements implying that her asthma was more problematic at a younger age.

• The results from the SSI indicate that although C feels she is currently adherent to her prescribed regimens, she has not been in the past. "Self as was" loads onto the same quadrant of the grid as the construct "out of control of asthma and medication" which is consistent with those results. "Me taking medication", however, is rated very similar to "self as was", whilst

"forget to take medication/don't take as prescribed" is rated as similar to self. These results would imply that C is less adherent than her statements in the SSI suggest.

- The laddering of "different – same" illustrate both positive and negative implications to this construct. This indicates an area of conflict and ambiguity within the grid, and specifically may indicate conflict and ambiguity in relation to the construal of "having asthma". "Restricted" and "feel understood", which appear in the grid, may represent core constructs.

Participant D:

D.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	13	3 months	Terbutaline sulphate	Budesonide

D.2 Semi-structured interview

(i) Asthma information/quotes

- "My asthma was quite bad until I was about 11years old."
- "I feel I've grown out of my asthma, it's not such a problem for me anymore!"
- "My parents still treat me like my asthma is really bad".

(ii) Medication information/quotes

- "I don't like having to take my medication at all! Other people don't have to carry round a bulky inhaler at school, it's embarrassing and makes me feel silly."
- "As I've got older its got worse to take it ....it's just got more embarrassing, and I forget about it more, especially when I go to sleep-overs and things."
- "I don't really feel that I need to take my medication anymore".

D.4 Grid data

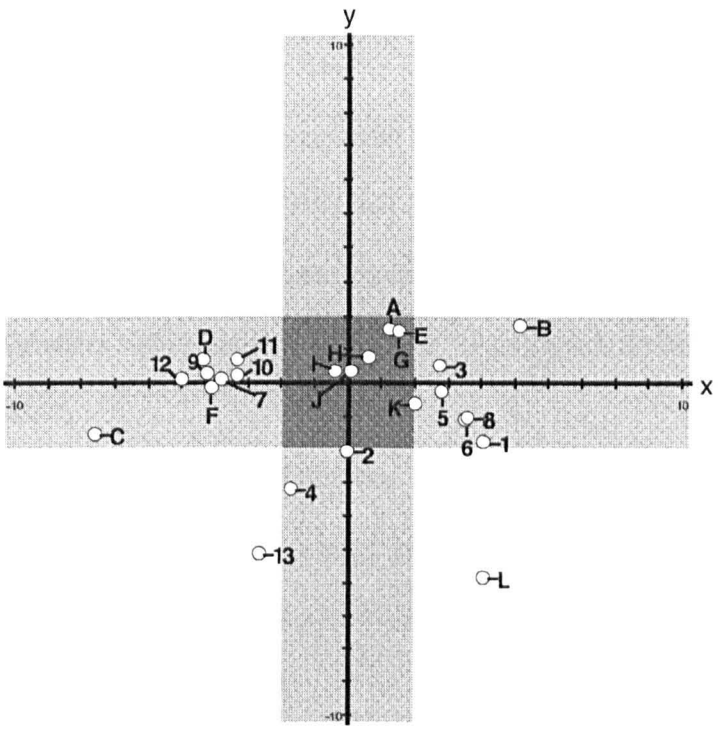
(i) Structural properties

- The grid shows a clear two dimensional structure, where Components 1 and 2 account for 62.52% and 20.45% of the variance respectively.

(ii) Construct loadings onto Component 1

- The construct "remembering I've got asthma – forgetting I've got asthma" accounts for the second highest percentage variance (11.1%) and loads significantly onto the x-axis so that the negative pole of the x-axis represents the construct pole "remembering I've got asthma".
- The positive pole of the x-axis is elaborated in terms of the construct "normal" which is significantly correlated with "confident" ($r = 0.94$); "having fun" ($r = 0.92$) and "able to do things" ($r = 0.88$).

D.3 Asthma Grid



x-Axis: Component 1 (62.52%)
y-Axis: Component 2 (20.45%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative values	Positive values
1	12	-5.0	11.11	remembering I've got asthma	forgetting I've got asthma
	9	-4.2	8.04	disappointed with myself	pleased with myself
	1	4.1	9.70	different	same
	7	-3.8	7.16	feel like I've got asthma	feel like a person without asthma
	8	3.6	7.16	struggling to do things	able to do things
	6	3.5	6.31	embarrassed	confident about doing things
	11	-3.3	6.21	not achieving	achieving
	10	-3.3	6.88	shy	confident
	5	2.8	4.23	feeling left out	having fun
	3	2.8	4.94	having to rely on others	feeling I can rely on myself
	13	-2.7	15.62	feeling tired	alive and enjoying myself
	4	-1.7	8.85	unfit	healthy
	2	0.0	3.81	left out	special
2	13	-5.2	15.62	feeling tired	alive and enjoying myself
	4	-3.3	8.85	unfit	healthy
	2	-2.1	3.81	special	left out

• The following constructs have significant correlations with "remembering I've got asthma" and therefore further elaborate the negative pole of the x-axis: "disappointed with myself" (r = 0.96); "not achieving" (r = 0.87); "shy" (r = 0.84); "feel like a person with asthma" (r = 0.89).

(iii) Construct loadings onto Component 2

• The construct "feel tired – feel alive and enjoying myself" accounts for the highest percentage variance (15.62%) and loads onto the y-axis where "feel tired" represents the negative pole. "Tired" correlates significantly with "unfit" (r = 0.64) which further elaborates the negative pole of the y-axis.

(iv) Element percentage sum of squares

• "Me with asthma" accounts for a larger percentage variance (9.23%) compared to "me without asthma" (2.39%) or "self" (2.24%).

(v) Element interrelationships

• "Self" is rated as significantly dissimilar to "self as was" (distance = 1.47) but is not significantly associated with "ideal self" (distance = 1.73).

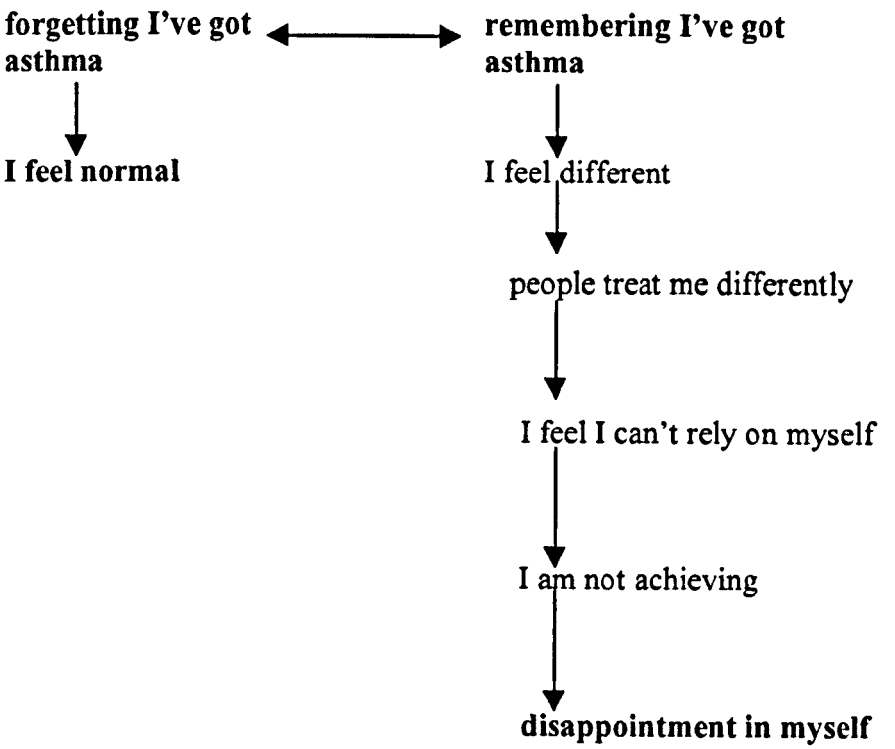
• "Self" is rated as significantly similar to "me without asthma" (distance = 0.15). There is no significant association with "me with asthma", however is rated as significantly similar to "child with asthma" (distance = 0.68).

• "Self" is rated significantly similar to "me not taking asthma medication" (distance = 0.15) and "forget to take medication/not taking medication as prescribed" (distance = 0.4). These elements load onto the positive pole of the x-axis which is defined by "feel normal".

• "Me taking medication" is rated significantly similar to "me with asthma" (distance = 0.43) and "self as was" (distance = 0.66). These elements load onto the negative pole of the x- axis defined by "remembering I've got asthma".

D.5 Laddering

"Forgetting I've got asthma – remembering I've got asthma" was laddered as this construct appeared in the elicitation procedure on more than one occasion.



D.6 Comparison of data sources: SSI; Asthma Grid; Laddering

• D's statements from the SSI indicated that she felt had grown out of her asthma and that it was no longer problematic. The results from the grid show that D has rated herself as similar to "me without asthma symptoms" but also similar to "child with asthma". The results also show that "self as was" is rated as similar to " having asthma". Therefore the SSI is corroborated to some extent, specifically D's asthma is less problematic than at a younger age. However, identification with "child with asthma" suggests that she still perceives herself as asthmatic.

• The results from the SSI indicate that she perceives taking medication negatively and refers to it as embarrassing. Such negative implications of "taking medication" are elaborated in the grid and laddering procedures. Specifically, taking medication is associated with remembering about asthma, which in turn ladders down to "feeling disappointed in self".

Participant E:

E.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	16	12 years	Salbutamol	Fluticasone propionate

E.2 Semi-structured interview

(i) Asthma information/quotes

- "My asthma is under control most of the time. It doesn't bother me."

(ii) Medication information/quotes

- "Its important that I take my medication cause then I won't get symptoms. If I forget to take it I worry that I will become poorly."

E.4 Grid data

(i) Structural properties

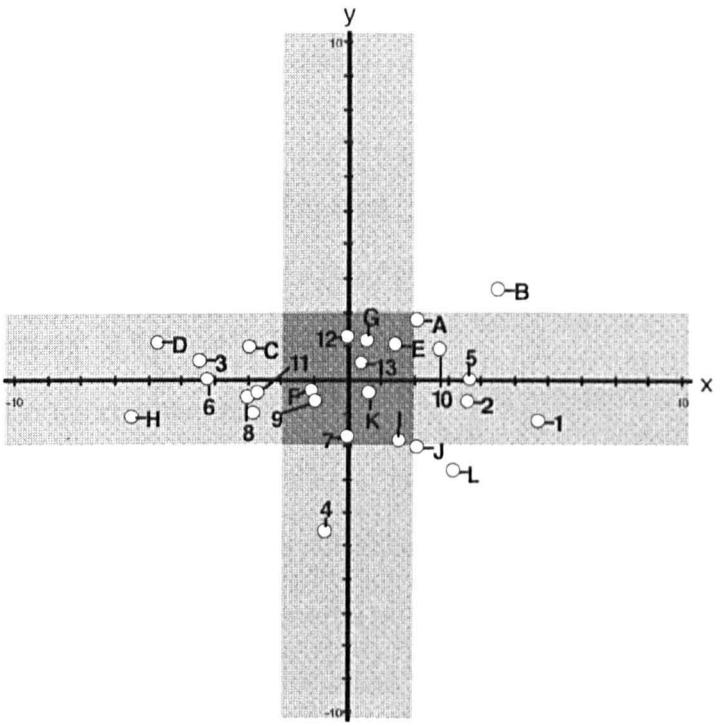
- The grid shows a clear two dimensional structure, where Components 1 and 2 account for 64.54% and 15.55% of the variance respectively.

(ii) Construct loadings onto Component 1

- The construct "normal - ill" accounts for the highest percentage variance (18.4%) and loads significantly onto the x-axis so that the positive pole of the x-axis represents the construct pole "normal".
- The negative pole of the x-axis is elaborated in terms of the construct "having asthma" which is significantly correlated with "bored" ($r = 0.75$); "uptight" ($r = 0.80$); "dependent" ($r = 0.72$); "angry" ($r = 0.66$) and "taking a backseat" ($r = 0.59$).
- The following constructs have significant correlations with "normal" and therefore further elaborate the positive pole of the x-axis: "awake and wanting to be with friends" ($r = 0.85$); "pleased with myself" ($r = 0.85$); and "not worried" ($r = 0.69$).

(iii) Construct loadings onto Component 2

E.3 Asthma Grid



x-Axis: Component 1 (64.54%)
y-Axis: Component 2 (15.55%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative values	Positive values
1	1	5.7	18.35	ill	normal
	3	-4.4	11.39	having asthma	not having asthma
	6	-4.2	10.27	bored	having a laugh
	5	3.7	7.29	annoyed with myself	pleased with myself
	2	3.6	9.94	tired, not wanting to do anything	awake wanting to be with friends
	8	-3.0	7.29	uptight	relaxed
	14	-2.8	6.42	dependent	independent
	10	2.8	5.43	worried	not worried
	11	-2.7	5.43	angry	calm
	9	-1.0	0.99	taking a backseat	reach my full potential
	4	-0.7	11.76	shy and retiring	confident
	13	0.4	0.46	different	included
	7	0.0	2.98	afraid to change	willing to give it a go
	12	0.0	1.99	quiet, subdued	chatty
2	4	-4.6	11.76	shy and retiring	confident
	7	-1.8	2.98	afraid to change	willing to give it a go
	12	1.3	1.99	chatty	quiet, subdued

• The construct "shy and retiring - confident" loads onto the y-axis, where "shy and retiring" represents the negative pole. "Afraid to change" correlates significantly with "shy and retiring" (r = 0.67).

(iv) Element percentage sum of squares

• "Me with asthma" accounts for a larger percentage variance (18.68%) compared to "me without asthma" (1.94%) or "self" (5.75%).

(v) Element interrelationships

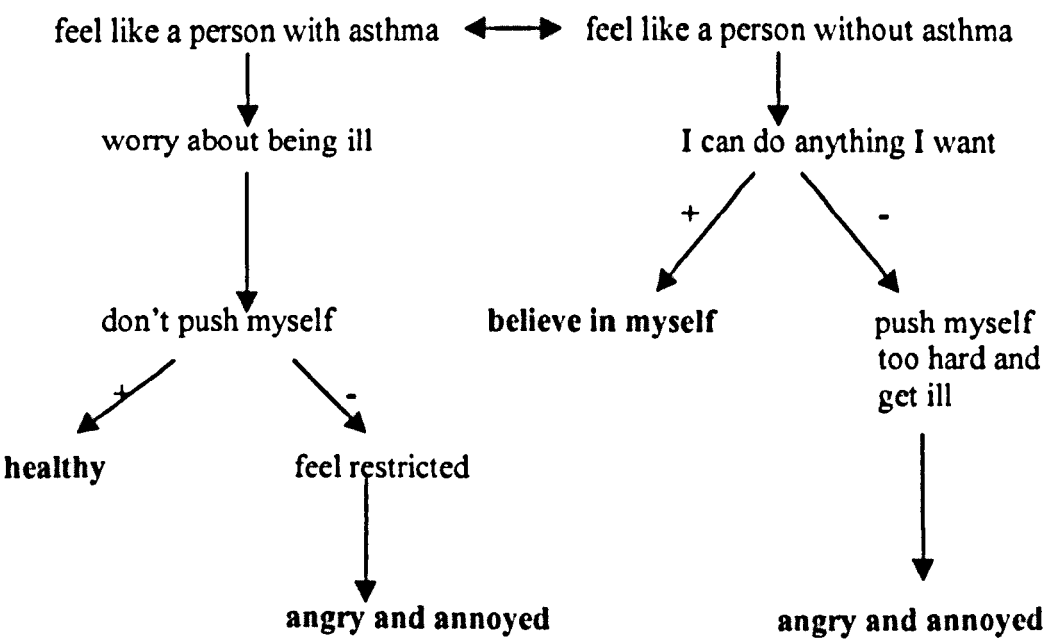
• Self is rated as significantly similar to "ideal self" (distance = 0.6) but is not rated significantly associated with "self as was" (distance = 1.02).

• "Self" is rated as significantly similar to "me without asthma" (distance = 0.37) and significantly dissimilar to "me with asthma" (distance = 1.42). However, "self" is rated significantly similar to "child with asthma" (distance = 0.66).

• "Self" is rated significantly dissimilar "forget to take medication/not taking medication as prescribed" (distance = 1.52). There is no significant association with "me taking medication".

E.5 Laddering

The construct "feel like a person with asthma – feel like a person without asthma" was laddered as it was elicited on more than one occasion.



E.6 Comparison of data sources: SSI; Asthma Grid; Laddering

- E's statements from the SSI indicated that her asthma was well controlled at the time of the interview. The results from the grid support this as it shows that E has rated herself as similar to "me without asthma symptoms". She rated herself as similar to "child with asthma" which indicates that she identifies herself as asthmatic.
- The results from the SSI indicate that E feels dependent on her medication for controlling her asthma. The grid is consistent with these results as the element "me with asthma" is associated with "forgetting to take medication". Both elements load onto the negative pole of the x-axis which is defined by "feeling bored, uptight, dependent, angry and taking a back seat".
- The grid and laddering procedures elaborate upon the SSI, and illustrate the negative implications of "feeling like a person with asthma" (e.g. feeling restricted and angry). However, it also shows how "feeling like a person with asthma" also has some positive implications, specifically it leads to maintenance of health.

Participant F:

F.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	13	2 years	Terbutaline sulphate	Fluticasone propionate

F.2 Semi-structured interview

(i) Asthma information/quotes

- "My asthma hasn't been too bad recently, but it used to be really bad. I could have an attack without any warning and that is really scary."
- F keeps a daily diary of peak flow readings.
- F has been admitted into hospital on numerous occasions because of acute/severe episodes of asthma.

(ii) Medication information/quotes

- "Sometimes, if my asthma has been fine, I think it's a waste of time to take my medication because it won't make any difference if I don't. However I know that I can go really bad very quickly if I don't take it".
- "Sometimes I get fed up with taking it but I do take it most of the time."

F.4 Grid data

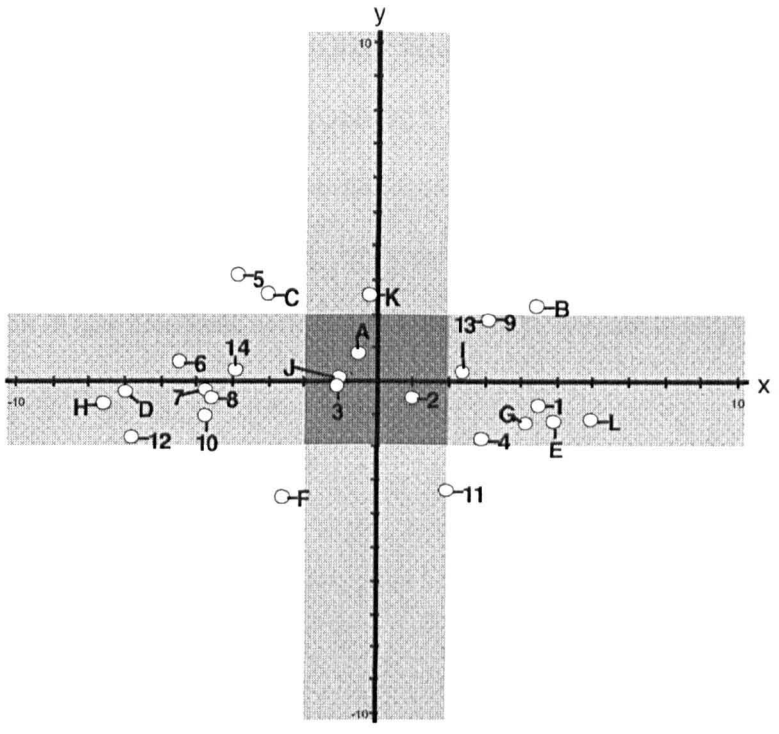
(i) Structural properties

- The grid shows a two dimensional structure, where Components 1 and 2 account for 64.13% and 10.54% of the variance respectively.

(ii) Construct loadings onto Component 1

- The construct "healthy - poorly" accounts for the highest percentage variance (15.4%) and loads significantly onto the x-axis so that the negative pole of the x-axis represents the construct pole "poorly".
- The positive pole of the x-axis is elaborated in terms of the construct "feel happy" which is significantly correlated with "free not to have to worry" ($r = 0.75$); "popular" ($r = 0.80$).

F.3 Asthma Grid



Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative values	Positive values
1	12	-6.8	15.38	poorly	healthy
	6	-5.5	11.94	trapped	independent
	7	-4.8	8.09	sad	happy
	10	-4.7	8.31	sad and boring	I am funny and make people laugh
	8	-4.6	6.78	ill	normal
	1	4.5	6.78	scared (shaky and panicky)	happy
	14	-3.9	4.85	feel like a person with asthma	normal
	5	-3.9	9.36	disabled	able to do everything
	9	3.1	5.06	trapped	free not to have to worry
	13	3.1	6.78	different	popular
	4	3.0	4.85	feel care for and supported	jealous
	11	2.0	5.99	perfect	normal
	3	-1.1	3.06	lonely	special
	2	1.0	2.77	excited	bored
2	11	-3.4	5.99	normal	perfect
	5	3.1	9.36	able to do everything	disabled
	9	1.8	5.06	trapped	free not to have to worry

• The following constructs have significant correlations with "poorly" and therefore further elaborate the negative pole of the x-axis: "I feel trapped" (r = 0.75); "sad" (r = 0.81); "ill" (0.89); "I feel sad and boring" (r = 0.81); "I feel like a person with asthma" (r = 0.92).

(iii) Construct loadings onto Component 2

• "Perfect – normal" is the only construct with loads significantly onto the y-axis, where the negative pole is defined by "normal". "Normal" correlates significantly with "feel jealous" (r = 0.62) which in turn correlates with "happy" (r = 0.71); "free not to have to worry" (r = 0.61) and "able to do things" (r = 0.61).

(iv) Element Percentage Variance

• "Me with asthma" accounts for a larger percentage variance (15.26%) compared to "me without asthma" (8.52%) or "self" (2.51%).

(v) Element interrelationships

• The element "self" is rated significantly similar to "self as was" (distance = 0.68) but shows no significant relationship with "ideal self" (distance = 0.81).

• "Self" is not significantly associated with "me with asthma"; "me without asthma"; "me taking medication"; "me not taking medication" or "forget to take medication". However, it is rated as significantly similar to "child with asthma" (distance = 0.58).

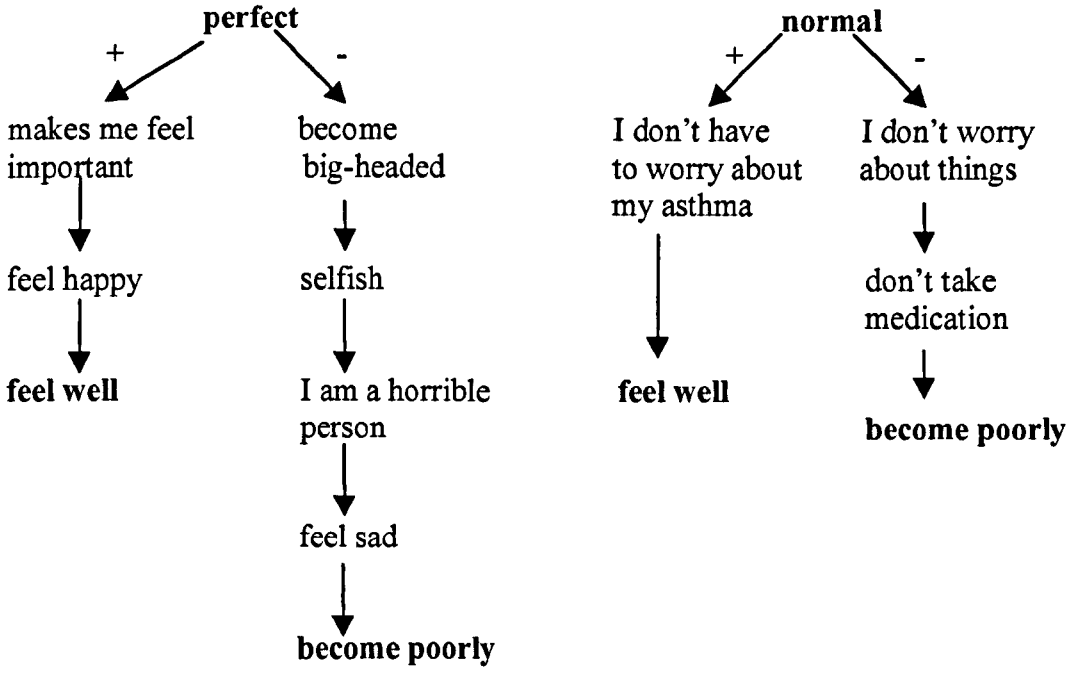
• The elements "ideal self", "me not taking medication" and "me without asthma" all load onto the positive pole of the x-axis which is defined by "healthy", "happy", "able to do things" and "free not to have to worry".

• The elements "me with asthma", and "me when I forget to take medication/don't take medication as prescribed" are rated as significantly similar (distance = 0.31) and load onto the negative pole of the x-axis which is defined by the construct "poorly".

• "As friends see me" loads onto the positive pole of the x-axis and is rated as significantly similar to "self". As parents see me is also rated as significantly similar to "self", however this element loads onto the negative pole of the x-axis.

F.5 Laddering

"Perfect – normal " was laddered as this was identified as an ambivalent construct.



F.6 Comparison of data sources: SSI; Asthma Grid and Laddering

- "Self" is not associated with either of the elements "having asthma" or "not having asthma", however, is rated as similar to "child with asthma". It can be hypothesised that F identifies herself as an asthmatic.
- The grid shows that "having asthma" is associated with constructs such as feeling sad, trapped and disabled.
- The results from the grid corroborate F's statements in the SSI as they indicate that she becomes symptomatic when she forgets to take her medication. The laddering of "perfect – normal" illustrates an area of conflict within F's construct system. All ladders terminate with "feeling well - feeling poorly". This construct accounts for the highest percentage variance of all construct elicited. Both of these factors suggest that this construct is superordinate. The laddering data shows direct links between affect and illness perception.

Participant G:

G.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	14	3 years	Terbutaline sulphate	Budesonide

G.2 Semi-structured interview

(i) Asthma information/quotes

- " I feel in control of my asthma now. I wasn't really in control of it when I was younger."

(ii) Medication information/quotes

- "I test out my asthma. I think I am growing out of it so when my symptoms go away I slowly stop taking my medication to test if I have grown out of it".
- "But it always seems to catch up with me if I don't take my medication for too long. I suppose I haven't grown out of it yet".
- At the time of the interview G commented that she was symptomatic and therefore was taking her medication.

G.4 Grid data

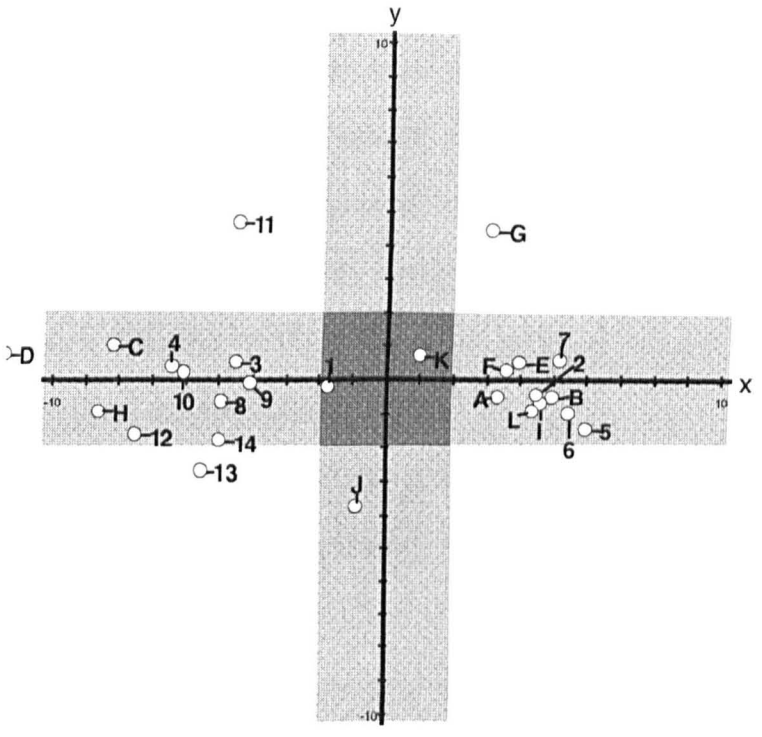
(i) Structural properties

- The grid shows a predominantly one-dimensional structure, where Components 1 and 2 account for 76.1% and 7.71% of the variance respectively. The grid represents a tightly organised construct system.

(ii) Construct loadings onto Component 1

- The construct "feel like a person with asthma – free of asthma and worries" accounts for the highest percentage variance (11.9%) and loads significantly onto the x-axis, where the negative pole is defined by "feel like a person with asthma".
- The construct "doing things I want" loads onto the positive pole of the x-axis and is significantly correlated with "joining in" ($r = 0.87$); "standing out" ($r = 0.78$) and "at ease with myself" ($r = 0.86$).

G.3 Asthma Grid



x-Axis: Component 1 (76.10%)
y-Axis: Component 2 (7.71%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative Values	Positive Values
1	12	-7.5	11.92	feel like a person with asthma	feel free of asthma and worries
	4	-6.4	9.18	people fussing over me	people easier with me
	10	-6.1	7.56	sitting around and worrying	getting on with my life
	5	6.0	8.41	can't do the things I want	doing things I want
	13	-5.5	8.74	special	average
	6	5.5	6.70	lonely, can't keep up	joining in
	7	5.2	7.48	hiding away, shy	standing out
	14	-5.0	6.31	unhealthy	healthy
	8	-4.9	6.83	different	normal
	11	-4.5	9.71	still going through the challenge	fulfilled
	3	-4.5	5.66	sad	happy
	2	4.5	4.50	angry with myself	at ease with myself
	9	-4.1	4.09	relying on people	independent
	1	-1.7	2.92	keep feelings inside	say what I feel
2	11	4.6	9.71	fulfilled	going through the challenge
	13	-2.7	8.74	special	average
	14	-1.8	6.31	unhealthy	healthy

• The following constructs have significant correlations with "feel like a person with asthma" and therefore further elaborate the negative pole of the x-axis: "people fussing over me" (r = 0.87); "different" (r = 0.82); "sitting around and worrying" (r =0.91); "relying on other people" (r = 0.87); "unhealthy" (r = 0.90); "special" (0.93); "sad" (r = 0.74).

(iii) Construct loadings onto Component 2

• The construct "fulfilled – still going through the challenge" loads onto the y-axis, where the negative pole is defined as "fulfilled".

(iv) Element percentage sum of squares

• "Me with asthma" accounts for a larger percentage variance (26.70%) compared to "me without asthma" (3.81%) or "self" (3.06%).

(v) Element interrelationships

• "Self' is rated as significantly similar to "ideal self" (distance = 0.27) and as significantly dissimilar to "self as was" (distance = 1.29). "Self" and "ideal self' load onto the positive poles of the x- and y-axes which are defined by "free of asthma and worries" and "standing out".

• "Self as was" is rated as significantly similar to "me when I forget to take medication/don't take it as prescribed" (distance = 0.66) and "me with asthma" (distance = 0.72). These load onto the negative pole of the x-axis.

• "Self" is rated significantly dissimilar to "me with asthma" (distance = 1.65) but significantly similar to "me without asthma" (distance = 0.33) and "me taking medication" (distance = 0.29).

• "Self" is also rated as significantly similar to "as friends see me" (distance = 0.21) but not to "as parents see me".

• "Self" is rated as significantly similar to "child with asthma" (distance = 0.43) and to "child without asthma" (distance = 0.49).

G.6 Comparison of data sources: SSI and Asthma Grid

• The results of the SSI indicate that although G feels in more control of her asthma then when she was younger, she is aware that she "hasn't grown out of it yet". The grid supports these results. "Self as was" is associated with "having asthma" and "self" is associated with "not

having asthma symptoms". "Self" however is associated with "child with asthma" and suggests that although her asthma is under control, she identifies as asthmatic.

- The gird shows that G sees herself as someone who takes asthma medication and doesn't forget to take it or doesn't take it deliberately. These results corroborate with her general comments given in the SSI which indicated that she was adherent at the time of the interview because she was symptomatic. It would be expected that her grid would show changes if taken at a time when asymptomatic.

Participant H:

H.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	16	12 months	Salubtamol	Beclamethasone dipropionate

H.2 Semi-structured interview

(i) Asthma information/quotes

- "I used to feel very panicky when having an attack. Now I feel more competent, I know what to do."
- "Asthma is just a part of me. I can't remember a time when I didn't have it. I wish I didn't have it, but I just accept it now."
- "I'm not as bothered about my asthma as I am my eczema. I get embarrassed about my eczema when out with my friends. The thing that most bothers me about my asthma is that I can't do some of the things I love, like horse riding".

(ii) Medication information/quotes

- "Sometimes I don't take my medication. It's mostly when I go to stay at friend's houses. I just don't want to have to be bothered with all that."
- "I know that I sometimes take my reliever too much. If my symptoms don't go away I just take more and more. It can make me feel shaky and weak."

H.4 Grid data

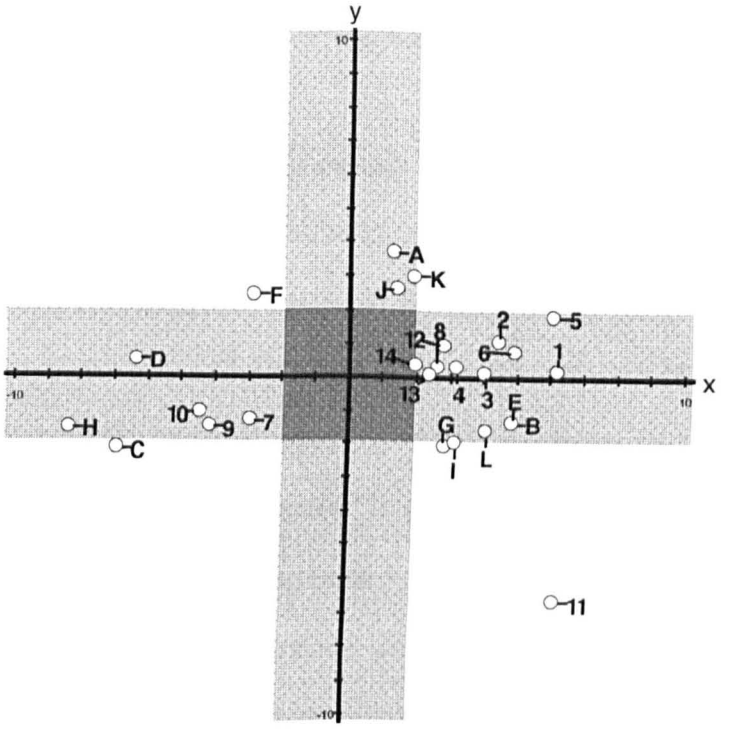
(i) Structural properties

- The grid shows a clear two dimensional structure, where Components 1 and 2 account for 69.91% and 15.54% of the variance respectively.

(ii) Construct loadings onto Component 1

- The construct "see myself with asthma – see myself without asthma" accounts for the highest percentage variance (23.1%) and loads significantly onto the x-axis so that the positive pole of the x-axis represents the construct pole "see myself without asthma".

H.3 Asthma Grid



x-Axis: Component 1 (68.76%)
y-Axis: Component 2 (16.40%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative Values	Positive Values
1	11	6.3	23.09	see myself with asthma	see myself without asthma
	1	6.2	10.78	annoyed	happy
	5	6.1	13.23	not able to do things and therefore don't want to	able to do things and happy about doing it
	6	5.0	7.86	stressed out	fine and happy
	2	4.5	6.23	feeling awful and scared	not scared
	10	-4.5	7.07	feel awful	feel bright and happy
	9	-4.2	5.69	aggressive	friendly
	3	4.1	6.25	self-conscious	full of myself
	4	3.2	3.51	others think i'm wierd	others think i'm nice and normal
	7	-3.0	3.87	not able to deal with my asthma	able to deal with my asthma
	12	2.8	4.06	tied down	independent
	8	2.6	3.51	feeling panicky	being calm
	13	2.4	2.97	different	normal
	14	2.0	1.88	ill	healthy
2	11	6.8	23.40	see myself with asthma	see myself without asthma
	7	1.6	3.77	able to deal with my asthma	not able to deal with my asthma
	8	-1.5	3.56	being calm	feeling panicky

• The negative pole of the x-axis is elaborated in terms of the construct "feel awful" which shows significant correlations with "being aggressive" (r = 0.94) and "not able to deal with my asthma" (r = 0.73).

• The construct "see myself without asthma" is significantly correlated with the construct "happy" (r = 0.64).

• The following constructs have significant correlations with "happy" and therefore further elaborate the positive pole of the x-axis: "able to do things" (r = 0.90); "others think I'm nice and normal" (r = 0.88); "fine and happy" (r = 0.89);"normal" (r = 0.76); "being calm" (r = 0.70); "healthy" (r = 0.73); "independent" (r = 0.66)

(iii) Construct loadings onto Component 2

• The construct "see myself with asthma – see myself without asthma" loads onto the y-axis where "see myself without asthma" represents the negative pole.

(iv) Element percentage sum of squares

• "Me with asthma" accounts for a larger percentage variance (13.96%) compared with "me without asthma" (7.03%) or "self" (4.63%).

(v) Element interrelationships

• Self is rated as significantly dissimilar to "self as was" (distance = 1.28). There is no significant association with "ideal self" (distance = 0.77).

• There is no significant association between "self" and "me with asthma" or "me without asthma".

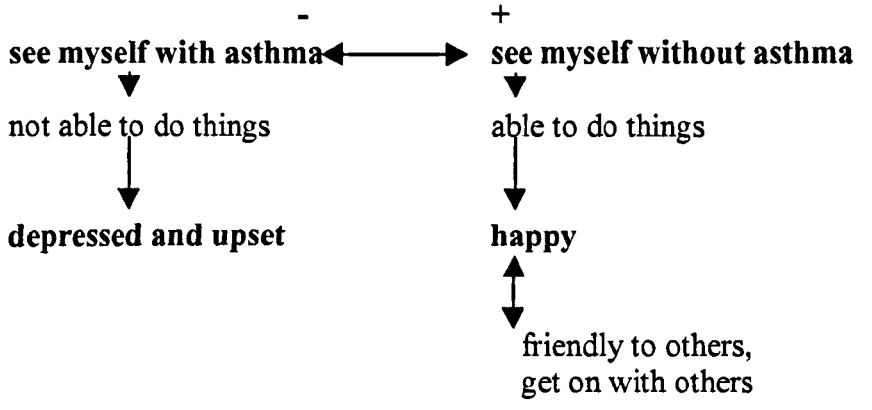
• "Self" is rated significantly similar to "me taking asthma medication" (distance = 0.7) and significantly dissimilar to "forget to take medication/not take as prescribed" (distance = 1.42).

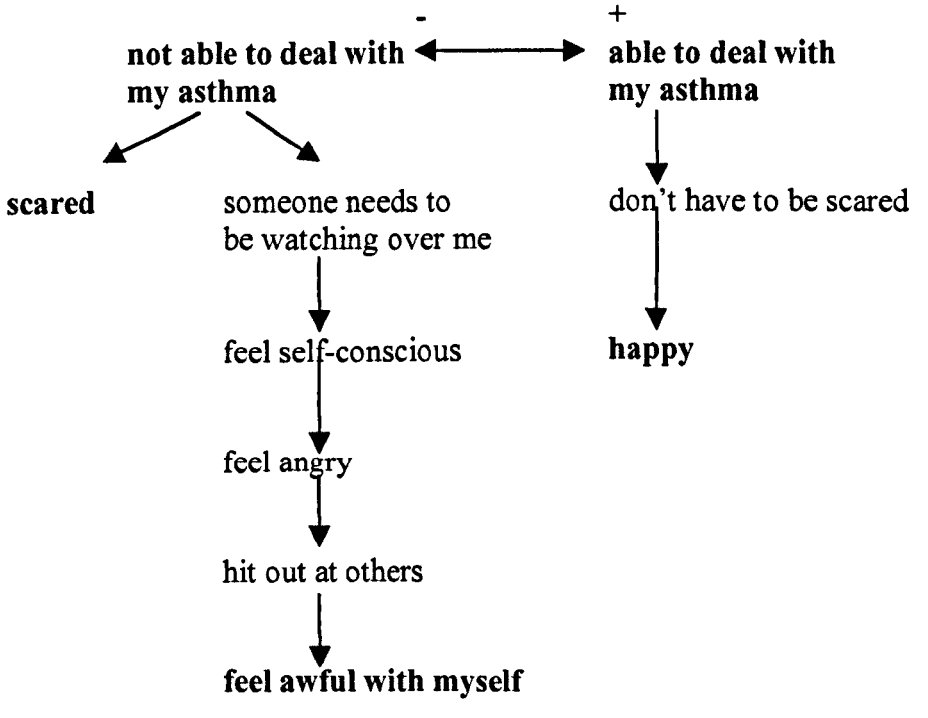
• "Ideal self" is rated significantly similar to "me without asthma" (distance = 0.00); "me not taking asthma medication" (distance = 0.35); "as friends see me" (distance 0.30) and "child without asthma" (distance = 0.21).

• "Self as was" is rated as significantly similar to "me with asthma" (distance = 0.62) and "forget to take medication/not take medication as prescribed" (distance = 0.69). These elements load onto the negative pole of the x-axis.

H.5 Laddering

"See myself with asthma – see myself without asthma" and "able to deal with my asthma – not able to deal with my asthma" were laddered as they were both elicited on more than one occasion.





H.6 Comparison of data sources: SSI; Asthma Grid; Laddering

• The grid supports H's statements in the SSI as they demonstrate that she perceives her asthma as less problematic at the time of the interview than when younger. Specifically, "self" loads

onto the axis defined by the constructs "feel like a person without asthma" and "feel able to cope with my asthma". Conversely "self as was" is defined by "feel like a person with asthma" and "unable to cope with my asthma".

- The element "forget to take medication" is associated with having asthma. "Taking medication" is not associated with "self", however it loads onto the axes defined by see myself a person with asthma. It can therefore be hypothesised that taking asthma medication is associated with feeling like a person with asthma, however forgetting to take medication is associated with having asthma symptoms. This pattern suggests that H is more likely to be adherent than non-adherent, and supports results from the SSI.
- The grid illustrates that having asthma is associated with feeling awful, being aggressive, not able to do things and feeling unable able to cope. The laddering data illustrates the implicit links between the constructs of the grid and identifies superordinacy of construing. For example, feeling like a person with asthma ladders down to "not able to do things" and "upset and depressed". It can be hypothesised that "upset and depressed" is superordinate. "Unable to cope" ladders to "feeling scared" and also to feeling "self-conscious", "angry and hit out" and "feel awful". In this case, "feeling scared" and "feel awful" are superordinate.

Participant I:

I.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	16	12 years	Salbutamol	Beclomethasone dipropionate

I.2 Semi-structured interview

(i) Asthma information/quotes

- "My asthma has gradually become worse as I have got older."
- "I am the only one with asthma in my immediate social group and sometimes I feel people don't really understand what its like to have it."
- "I" is very involved sports and plays netball for her school team. "It annoys me when my coach and other team members push me too hard".

(ii) Medication information/quotes

- "I take my medication because I've been told to by my doctor. I don't really question what my doctor tells me to do."
- "If I don't take my preventer, or I forget to take it, then I can feel the difference very quickly. For example, if I forget to take it before I go to bed I am wheezy when I get up in the morning."
- "I prefer to take my medication and be well rather than not take it and be ill."

I.4 Grid data

(i) Structural properties

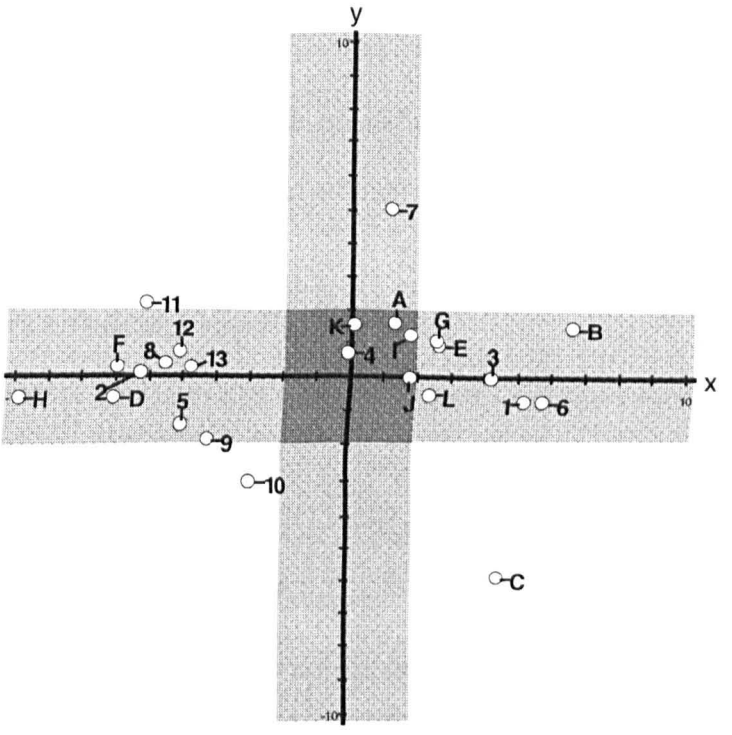
- The grid shows a clear two dimensional structure, where Components 1 and 2 account for 73.37% and 11.97% of the variance respectively.

(ii) Construct loadings onto Component 1

The construct "being panicky – being calm" loads most significantly onto the x- axis so that the negative pole of the x-axis represents the construct pole "being panicky".

- The positive pole of the x-axis is elaborated in terms of the construct "asthma is not in the way" which shows significant correlations with "doing what I want" ($r = 0.92$) and "feeling understood" ($r = 0.82$).

I.3 Asthma Grid



x-Axis: Component 1 (73.37%)
y-Axis: Component 2 (11.97%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative Values	Positive Values
1	2	-6.3	12.67	being panicky	being calm
	11	-6.2	13.50	feel like a person with asthma	feel like a person without asthma
	6	5.8	9.42	asthma is inconvenient	asthma is not in the way
	8	-5.5	8.67	out of control	in control
	1	5.3	8.40	restricted in what you do	doing what you want
	12	-5.1	7.89	feel different	feel the same as others
	5	-5.0	7.21	everything is going wrong	everything is alright
	13	-4.7	6.80	unhealthy	healthy
	3	4.2	5.78	annoyed that others don't understand	feeling understood
	9	-4.2	6.70	unsuccessful, a failure	successful
	10	-2.9	4.83	reliant on people	independent
	7	1.2	6.87	feel like I don't have an opinion	feel mature and I have an opinion
	4	0.0	1.28	unsympathetic	people sympathetic towards me
2	7	5.0	6.87	feel like I don't have an opinion	feel mature and I have an opinion
	10	-3.0	4.83	reliant on people	independent
	11	2.2	13.50	feel like a person without asthma	feel like a person with asthma

• The following constructs have significant correlations with "being panicky" and therefore further elaborate the negative pole of the x-axis: "every things wrong" (r = 0.87); "out of control" (r = 0.85); "unhealthy" (r = 0.84);"different" (r = 0.79); "unsuccessful, a failure" (r = 0.60); and "feel like a person with asthma" (r = 0.60). The construct "feel like a person with asthma –feel like a person without asthma" accounts for the highest percentage variance (13.5%) within the grid.

(iii) Construct loadings onto Component 2

• The construct "feel like I don't have an opinion – feel mature and I have an opinion" loads onto the y-axis where "feel like I don't have an opinion" represents the negative pole and shows a significant correlation with "reliant on people" (r = 0.84).

(iv) Element percentage sum of squares

• "Me with asthma" accounts for a larger percentage variance (14.97%) compared to "me without asthma" (2.68%) or "self (1.19%).

(v) Element interrelationships

• There are no significant relationships between "self" and "self as was" (distance = 0.98) or "ideal self" (distance = 0.74).

• "Self" is rated as significantly similar to "me without asthma" (distance = 0.29) but is not significantly associated with "me with asthma" (distance = 1.12).

• "Self" is rated significantly similar to "me not taking asthma medication" (distance = 0.24) and significantly dissimilar to "forget to take medication/not taking medication as prescribed" (distance = 1.38).

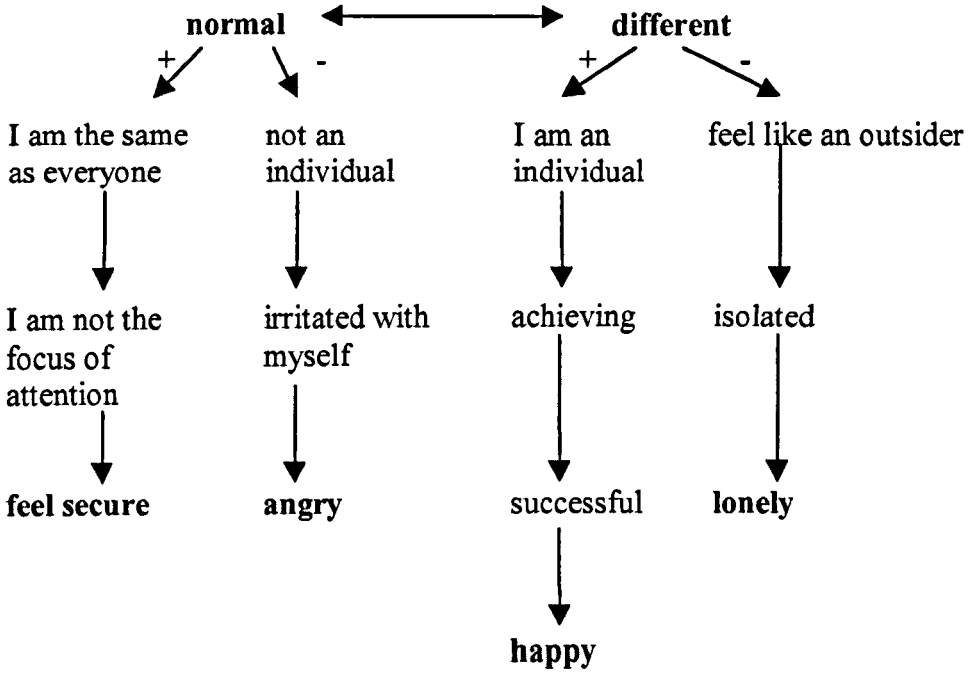
• "Ideal self" is rated significantly similar to "me without asthma" (distance = 0.57); "me not taking asthma medication" (distance = 0.59); "as friends see me" (distance 0.66) and "child without asthma" (distance = 0.64). These elements load onto the positive pole of the x-axis.

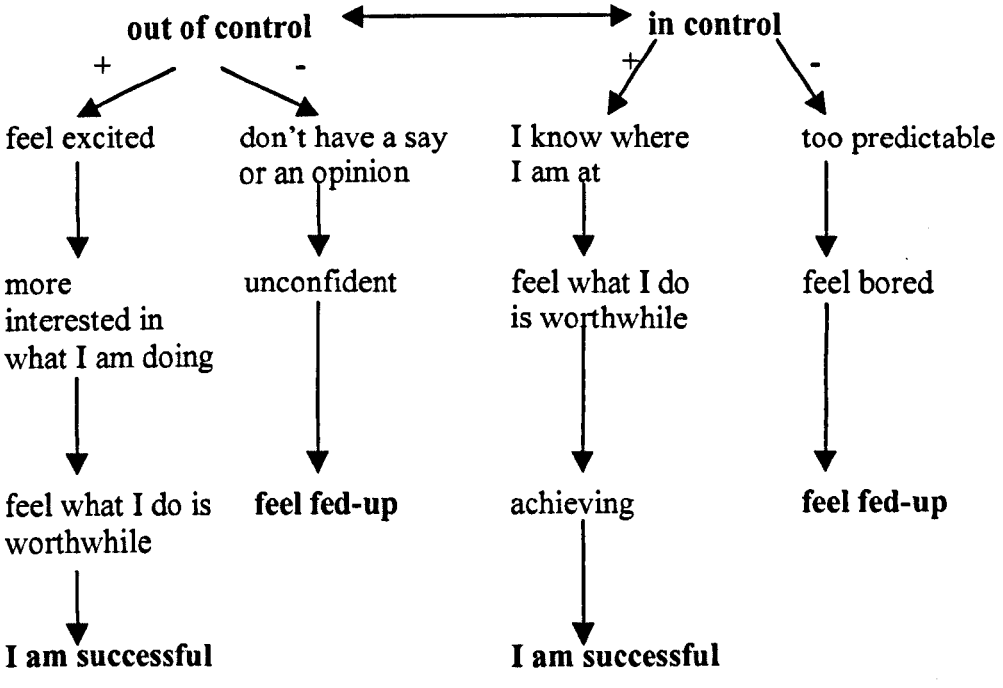
• "Self as was" is rated as significantly dissimilar to "me with asthma" (distance = 1.56) and "me taking asthma medication" (distance = 1.58). "Self as was" loads onto the positive pole of the x-axis defined by "asthma is not in the way", and the negative pole of the y-axis defined by "feel like I don't have an opinion".

• "Me with asthma" loads onto the negative pole of the x-axis which is defined by the construct "being panicky". It is rated as significantly similar to "me taking asthma medication"(distance = 0.63) and "forget to take medication/not taking medication as prescribed" (distance = 0.53)

I.5 Laddering

"Normal – different" and "in control – out of control" were laddered as they were identified as ambivalent constructs.





I.6 Comparison of data sources: SSI; Asthma Grid; Laddering

- The results from the SSI indicate K's asthma has become more severe over recent years. The grid is consistent with these results; "self as was" is not associated with either "self" or "having asthma" which is associated with having asthma.
- I's statements in the SSI suggests that she is adherent to prescribed medication regimens. Within the grid, having asthma is associated with forgetting to take medication. However, taking medication is also associated with having asthma. This pattern of results suggests ambivalent adherence behaviour which is not consistent with the results of the SSI.
- Having asthma is associated with feeling panicky, being out of control, and feeling different. The ladders of "being in control – being out of control" and "feeling different – feeling the same as others" show both positive and negative implications to these constructs. This indicates an area of conflict and ambiguity within the grid, and specifically may indicate conflict and ambiguity in relation to the construal of "having asthma".

Participant J:

J.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
male	15	17 months	Terbutaline sulphate	Montelukast

J.2 Semi-structured interview

(i) Asthma information/quotes

- "I feel OK about my asthma at the moment. It's not as bad as it used to be and it doesn't stop me from doing most of the things that I want to do."
- "Sometimes I can't keep up with my friends when we run around but I'm not too bothered about that."

(ii) Medication information/quotes

- "My medication used to make me aggressive when I was younger".
- J's mother commented "the medication he takes now has made him put on weight, that's the only concern I have about it."
- "I don't mind taking it. Sometimes I forget but it's not difficult to take it. I only have to take one tablet when I get up in the morning".

J.4 Grid data

(i) Structural properties

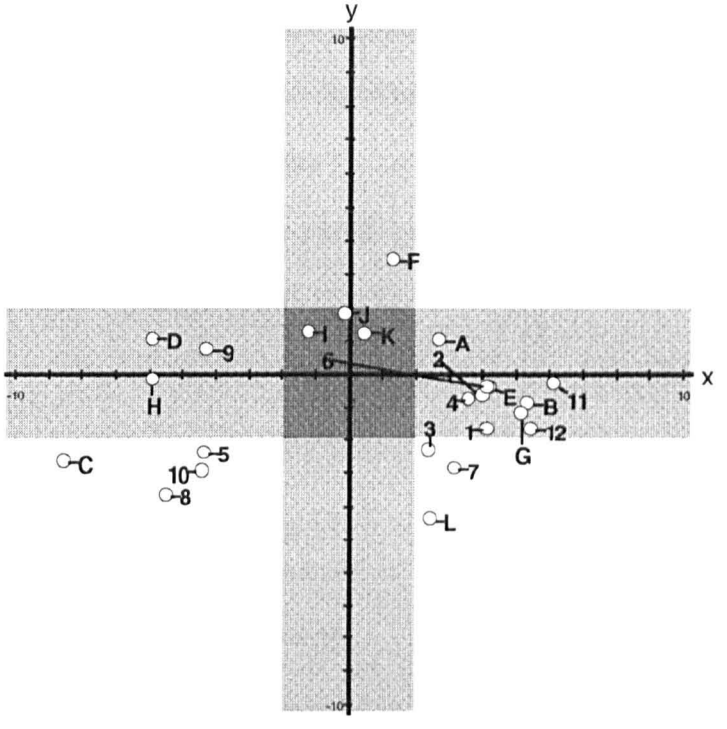
- The grid shows a clear two dimensional structure, where Components 1 and 2 account for 64.37% and 13.62% of the variance respectively.

(ii) Construct loadings onto Component 1

- The construct "difficult to breath – easy to breath" (14.6%) loads most significantly onto the x-axis where "easy to breath" represents the positive pole. The negative pole of the x-axis is defined by "other people making my decisions" and is significantly correlated with "not able to do things" ($r = 0.65$); irresponsible ($r = 0.79$) and immature ($r = 0.85$).

The following constructs have significant correlations with "easy to breath" and therefore further elaborate the negative pole of the x-axis: "feel in control" ($r = 0.77$); "not worried" ($r = 0.9$); "being pleasant" ($r = 0.79$).

J.3 Asthma Grid



x-Axis: Component 1 (64.37%)
y-Axis: Component 2 (13.62%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative Values	Positive Values
1	11	6.2	14.59	difficult to breath	easy to breath
	8	-5.5	12.84	other people making my decisions	making all my own decisions
	12	5.5	12.36	different	normal
	10	-4.4	9.82	irresponsible	responsible
	5	-4.4	8.17	immature	mature
	9	-4.3	6.12	not able to do things	able to do things
	6	4.2	5.69	being aggressive and nasty	being pleasant
	1	4.1	8.53	frustrated	calm
	2	4.0	5.41	feel wierd, dizzy and out of control	feel in control
	4	3.6	4.47	worried	not worried
	7	3.2	6.79	"why does it happen to me?"	"I've just got to live with it!"
	3	2.4	5.21	feel like a person with asthma	feel like a normal person
2	8	-3.7	12.84	other people making my decisions	making all my own decisions
	10	-3.0	9.82	irresponsible	responsible
	7	-2.9	6.79	"I've just got to live with it"	"why does it happen to me?"

(iii) Construct loadings onto Component 2

• The construct "other people make my decisions – make my own decisions" loads onto the y-axis where "other people make my decisions" represents the negative pole.

(iv) Element Percentage Variance

• "Me with asthma" accounts for a larger percentage variance (12.03%) compared to "me without asthma" (6.12%) or "self" (3.32%).

• "Forget to take medication/not taking medication when I should" accounts for a higher percentage variance (13.32%) compared to "me taking medication" (7.13%).

(v) Element interrelationships

• "Self" is rated significantly dissimilar to "self as was" (distance =1.52) and significantly similar to "ideal self" (distance = 0.55).

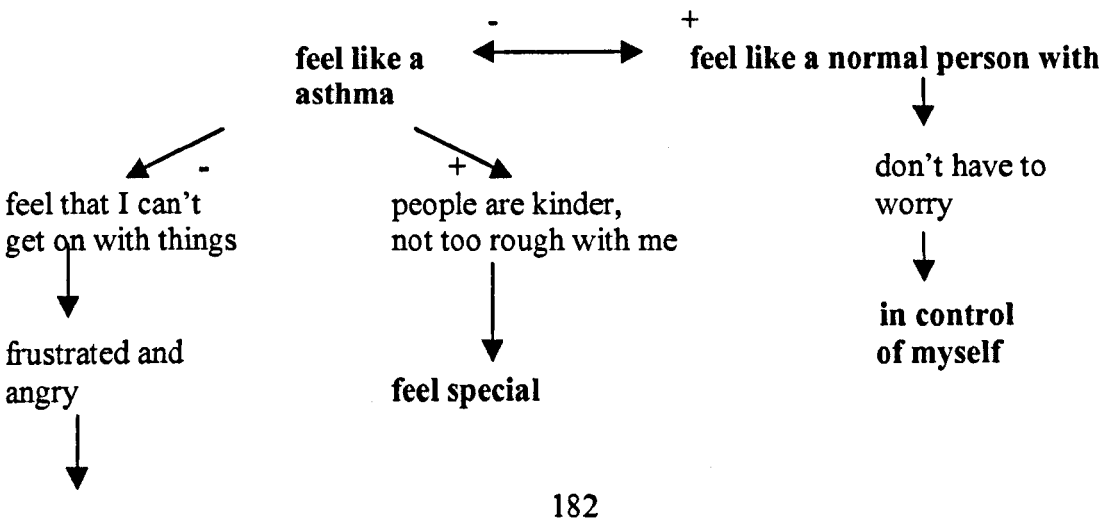
• "Self" is rated as significantly similar to "me without asthma" (distance = 0.43) but is not rated as significantly dissimilar to "me with asthma" (distance = 1.15).

• "Self" is rated significantly similar to "me taking asthma medication" (distance = 0.62). There is no significant association between "self" and "forget to take medication/not taking medication when I should" (distance = 1.15).

• 'Ideal self' is rated as significantly similar to the elements 'not taking medication' and 'me without asthma' (distances 0.28; 0.43). These elements load onto the positive pole of the x-axis.

J.5 Laddering data

Feel like a person with asthma was laddered as it was elicited on more than one occasion.



aggressive and
behave like an idiot

↓

irresponsible

↓

untrustworthy

J.6 Comparison of data sources: SSI; Asthma Grid; Laddering

• The results from the SSI indicate that J perceived his asthma to be less problematic at the time of the interview than when he was younger. The grid shows that having asthma is associated with "self as was", and that "self" is associated with not having asthma. "Self" is associated with the element "child with asthma". These results are consistent with those of the SSI. They suggest that although J perceives himself as a person with asthma, he recognises that he is predominantly asymptomatic.

• The grid illustrates an adherent pattern of health behaviour. Specifically, "self" is associated with taking medication and forgetting to take medication is associated with having asthma symptoms. These results are consistent with those from the SSI.

• The results from the grid and ladders illustrate how having asthma is associated with feeling aggressive, angry, irresponsible and untrustworthy. These results corroborate information from the SSI, specifically in relation his self-perception as behaving aggressively as a younger child.

• The laddering data builds upon the results from the SSI and the grid. Specifically it illustrates both positive and negative implications to the construal of asthma and may represent an area of ambiguity within J construct system.

Participant K:

K.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	17	15 years	Salbutamol	Beclomethasone dipropionate

K.2 Semi-Structured Interview

(i) Asthma information/quotes

- "I feel I cope quite well with my asthma in general."
- "I don't really like people to know that I have asthma. I don't want people to treat me differently by making a fuss or being sympathetic."
- "I've noticed that when I'm stressed out my asthma is worse. Last year during my exams it was definitely worse than normal."

(ii) Medication information/quotes

- "When I take my medication I'm alright and my asthma is under control."
- "When I don't take my medication I feel chesty and I get mad with myself for not taking it."

K.4 Grid data

(i) Structural properties

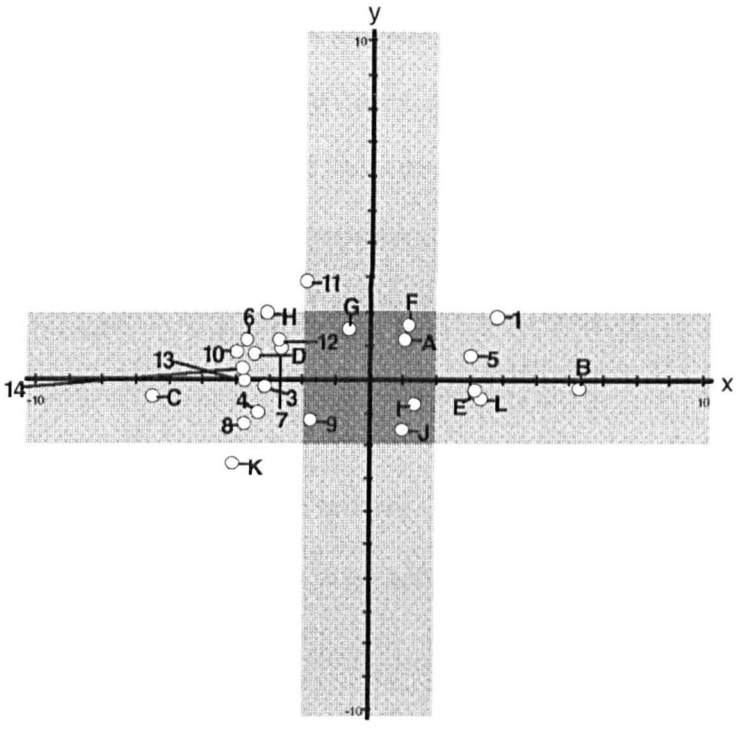
- The grid shows a two-dimensional structure where Components 1 and 2 account for 69.01% and 9.66% of the variance respectively.

(ii) Construct loadings onto Component 1

The construct "feel like a person with asthma – feel like a normal everyday person" loads most significantly onto the x-axis so that the negative pole of the x- represents the construct pole "feel like a person with asthma".

- The positive pole of the x-axis is elaborated in terms of the construct "treating me like a normal person" which is significantly correlated with "happy and content with myself" ($r = 0.70$). This accounts for the highest percentage variance (10.7%) within the grid.

K.3 Asthma Grid



x-Axis: Component 1 (69.01%)
y-Axis: Component 2 (9.66%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative Values	Positive Values
1	10	-4.0	8.37	feel like a person with asthma	normal everyday person
	1	3.8	10.66	people fussing over me	treating me like a normal person
	14	-3.8	7.29	unconfident in myself	confident
	13	-3.7	6.94	unhealthy	healthy
	8	-3.7	8.37	not sure of myself	sure of myself
	6	-3.7	8.80	different	feel normal and part of a group
	4	-3.3	6.94	feel vulnerable	feel safe
	2	3.2	7.29	angry	happy and enjoying myself
	3	-3.1	6.94	not coping with my asthma by trying to forget	coping with my asthma
	5	3.1	6.01	worried	happy and content
	12	-2.7	4.96	dependent	independent
	7	-2.7	4.15	feel like a loser	feel i'm achieving
	11	-1.9	6.94	special	normal
	9	-1.7	6.36	negative about myself	positive about myself
2	11	2.8	6.94	normal	special
	1	1.8	10.66	people fussing over me	treating me like a normal person

• The following constructs have significant correlations with "feel like a person with asthma" and therefore further elaborate the negative pole of the x-axis: "unconfident" (r = 0.95); "dependent" (r = 0.79); "unhealthy" (r = 0.92);"different" (r = 0.87); "feel like a loser" (r = 0.87); "vulnerable" (r = 0.79) and "not coping with my asthma and trying to forget" (r = 0.73).

(iii) Construct loadings onto Component 2

• The construct "normal - special" loads onto the y-axis where "special" represents the positive pole and shows significant correlations with "feel like a loser"(r = 0.64) and "dependent" (r = 0.66).

(iv) Element percentage sum of squares

"Me with asthma" accounts for a larger percentage variance (7.87%) compared to "me without asthma" (6.55%) or "self" (2.98%).

(v) Element interrelationships

• "Self" is rated significantly dissimilar to "self as was" (distance = 1.31) however has no significant association with "ideal self" (distance = 0.99).

• "Self" is rated as significantly similar to "me without asthma" (distance = 0.66) but is not rated as significantly dissimilar to "me with asthma" (distance = 0.85).

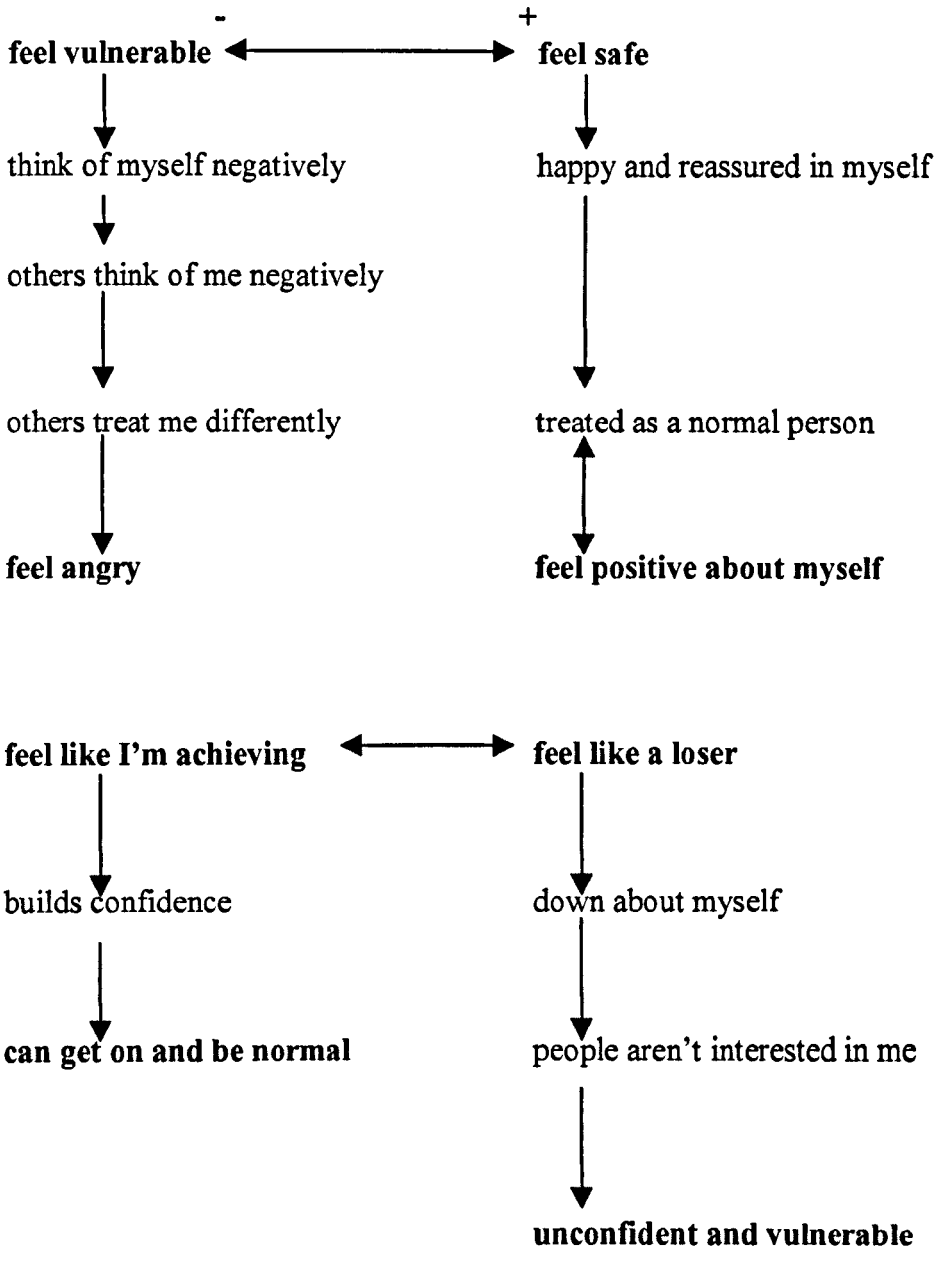
• "Self" is rated significantly similar to "me taking asthma medication" (distance = 0.55) however has no significant association with "forget to take medication/not taking medication as prescribed" (distance = 0.83).

• "Ideal self" is rated significantly dissimilar to "me with asthma" (distance = 1.62). It is rated significantly similar to "child without asthma" (distance = 0.6) and both load onto the positive pole of the x-axis.

• "Me with asthma" loads onto the negative pole of the x-axis, which is defined by the construct "feel like a person with asthma". It is rated as significantly similar to "forget to take medication/not taking medication as prescribed" (distance = 0.62).

K.5 Laddering

The constructs "feel vulnerable – feel safe" and "feel like I'm achieving – feel like a loser" were laddered as they were elicited on more than one occasion.



K.6 Comparison of data sources: SSI; Asthma Grid; Laddering

• K's statements within the SSI indicated that she was coping with her asthma at the time of the interview. The grid supports this result, specifically "self " is associated with the element "not having asthma". "Having asthma" is associated with a number of negative constructions such as feeling vulnerable, dependent, unconfident and different.

- K's statements within the SSI indicate that she feels dependent on her medication to maintain her health in relation to asthma. These results are supported by the grid as "self" is associated with "taking medication" and "forgetting to take medication/not take as prescribed" is associated with "having asthma".
- K's statements within the SSI indicate that she does not want others to know about her asthma, or to be treated differently because of her asthma. Concerns about other people's perceptions of her are a prominent feature of both laddered constructs. Specifically, these ladders illustrate that constructs such as "vulnerable" or "like a loser" lead to negative construal of "self" by others, which in turn governs her own "self" valuations.

Participant L:

L.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	16	15 years	Salbutamol	Fluticasone propionate

L.2 Semi-structured interview

(i) Asthma information/quotes

- L introduced herself with the statement "my asthma doesn't bother me at all. I don't think I've really got it".
- Later on she made reference to specific examples in which she had been out of breath "the other week I got wheezy when I was biking and couldn't keep up with my sister". She added, however, "I don't call that asthma, I was just a bit wheezy".

(ii) Medication information/quotes

- "I find it boring to take asthma medication."
- "I don't think I need it. Sometimes I go for a week without taking it and I am no different".

L.4 Grid data

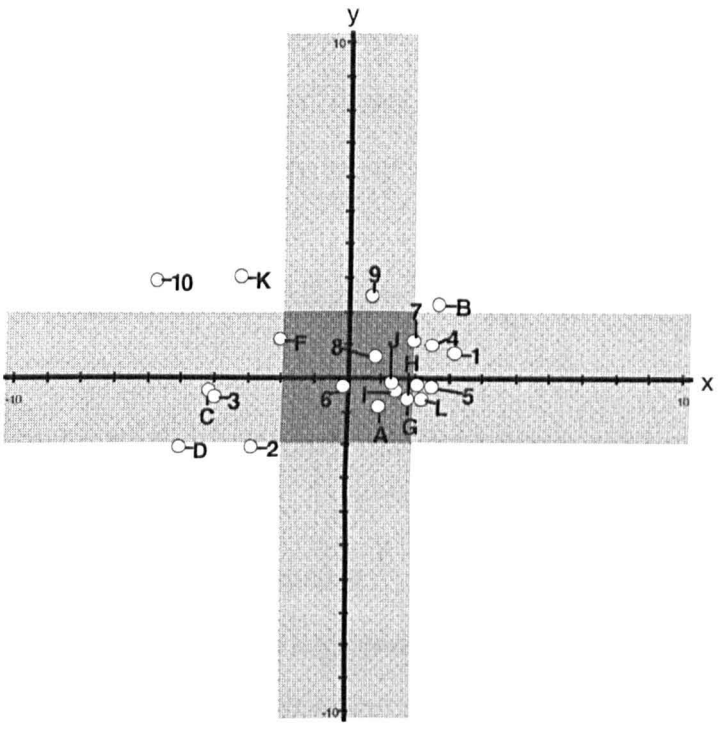
(i) Structural properties

The grid shows a predominantly one-dimensional structure where Components 1 and 2 account for 62.41 % and 13.98 % of the variance respectively.

(ii) Construct loadings onto Component 1

- The construct "feel like a person with asthma – don't feel like a person with asthma" loads most significantly onto the x-axis so that the positive pole of the x-axis represents the construct pole "don't feel like a person with asthma". This construct accounts for the highest construct percentage variance in the grid (30.35%).
- The negative pole of the x-axis is elaborated in terms of the construct "feeling bored" which is

L.3 Asthma Grid



x-Axis: Component 1 (62.41%)
y-Axis: Component 2 (13.98%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative Values	Positive Values
1	10	-5.8	30.35	feel like a person with asthma	don't feel like a person with asthma
	3	-4.0	14.14	feeling bored	having fun
	1	3.2	11.96	unhealthy	healthy
	2	-2.8	10.37	scared	happy
	5	2.5	7.54	unfit	sporty, active
	4	2.5	7.78	different	normal
	7	2.0	4.71	upset	happy
	8	0.8	1.59	lonely	special
	9	0.7	7.54	dependent	independent
	6	-0.1	4.01	loud	quiet
2	10	2.9	30.35	don't feel like a person with asthma	feel like a person with asthma
	9	2.4	7.54	dependent	independent
	2	-2.1	10.37	scared	happy

significantly correlated with "feeling scared" (r = 0.70). This accounts for the highest percentage variance (10.7%) within the grid.

- The construct "healthy - unhealthy" further elaborates the positive pole of the x-axis and is significantly correlated with: "sporty, active" (r = 0.92); "feel happy" (r = 0.60 and "special" (r = 0.61).

(iii) Construct loadings onto Component 2

- The construct "feel like a person with asthma – don't feel like a person with asthma" loads most significantly onto the y-axis where "feel like a person with asthma" represents the positive pole.

(iv) Element percentage sum of squares

- "Me with asthma" accounts for a larger percentage variance (22.37%) compared to "me without asthma" (4.22%) or "self" (3.04%). .

(v) Element interrelationships

- "Self" shows no significant associations with "ideal self" (0.88) or "self as was" (distance = 1.17)
- "Self" is rated as significantly similar to "me without asthma" (distance = 0.44) but is not rated as significantly dissimilar to "me with asthma" (distance = 1.26).
- "Self" is rated significantly similar to "me not taking asthma medication" (distance = 0.39) and "forget to take medication/not taking medication as prescribed" (distance = 0.39).
- "Self is rated as significantly similar to "as parents see me" (distance = 0.52) and "as friends see me" (distance = 0.56).
- "Self is rated as closer to "child without asthma" (distance = 0.68) than "child with asthma" (distance = 1.20) although these associations are not significant.

L.5 Laddering

No constructs were laddered.

L.6 Comparison of data sources: SSI; Asthma Grid.

- The results of the SSI indicate that L does not see herself as someone who has asthma. The grid supports these results, specifically "self" is associated with the element "not having asthma". Further, the grid elaborates the constructs associated with asthma, these are "feeling bored" and "feeling scared".
- The results of the SSI indicate that L does not perceive her medication to be effective and therefore "doesn't need it". "Self" is associated with "forget to take medication/don't take as prescribed" which suggests a pattern of non-adherent medication. These results support those from the SSI.

Participant M:

M.1 Demographics

Gender	Age (years)	Age at Diagnosis	Current Medication	
			Reliever	Preventative
female	14	2 years	Terbutaline sulphate	Budesonide

M.2 Semi-structured interview

(i) Asthma information/quotes

- "At the moment my asthma doesn't really bother me much at all."
- My asthma can be triggered by a shock. I had an attack quite recently after our school bus crashed. My asthma came on really bad and I was terrified because I couldn't breath".

(ii) Medication information/quotes

- "I'm not too bothered about my medication. I just take it.
- "Sometimes I forget to take it."

M.4 Grid data

(i) Structural properties

- The grid illustrates a clear two dimensional structure, where Components 1 and 2 account for 71.27% and 16.76% of the variance respectively.

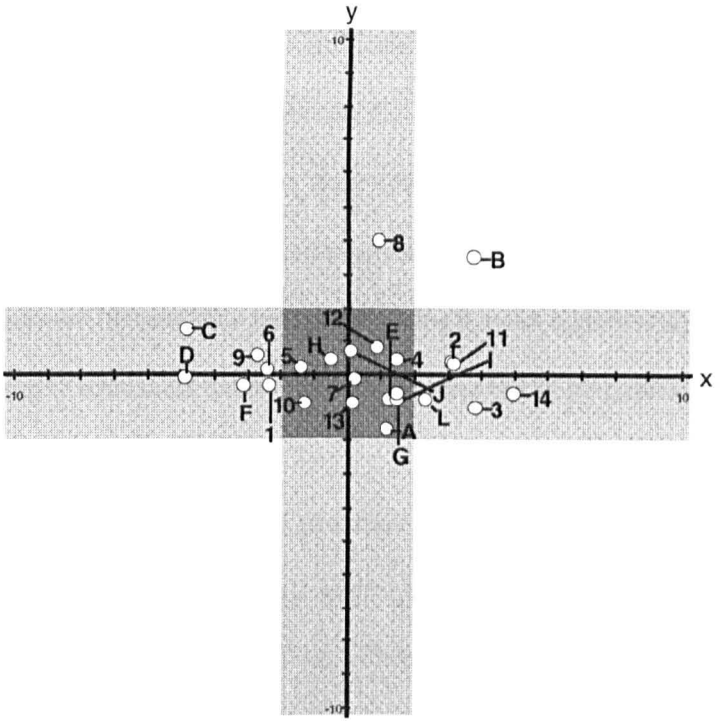
(ii) Construct loadings onto Component 1

The construct "feel like a person with asthma –feel like a person without asthma" loads most significantly onto the x-axis so that the positive pole of the x-axis represents the construct pole "feel like a person without

asthma". This construct accounts for the highest construct percentage variance in the grid (21.6%).

- The negative pole of the x-axis is elaborated in terms of the construct "abnormal" which is

M.3 Asthma Grid



x-Axis: Component 1 (71.27%)
y-Axis: Component 2 (16.76%)

Element Key:
A= Self **B**=Ideal Self **C**=Self As Was **D**=Me with asthma **E**=Me without asthma
F=Me taking medication **G**=Me not taking Medication **H**=Forget to take medication
I=As friends see me **J**=As parents see me **K**=Child with asthma **L**=Child without asthma

Comp	Const	Load	Var%	Negative Values	Positive Values
1	14	5.0	21.58	feel like a person with asthma	feel like a person without asthma
	3	3.9	13.90	scared	content/comfortable
	11	3.2	9.04	feel restricted	unrestricted
	2	3.2	8.97	on my own, different	accepted
	9	-2.7	7.33	abnormal	normal
	6	-2.4	7.40	self-conscious	confident
	1	-2.3	5.68	not safe	safe
	4	1.5	3.01	unfit	healthy
	5	-1.4	1.85	boring	outgoing
	10	-1.3	2.40	incomplete	happy in myself
	8	0.9	13.97	dependent	independent
	12	0.9	1.64	angry	calm
	7	0.3	0.75	supported	not supported
	13	0.2	2.47	special	not special
2	8	4.0	13.97	dependent	independent
	3	-1.0	13.90	content/comfortable	scared
	13	-0.9	2.47	not special	special

significantly correlated with "self-conscious" (r = 0.73); boring (r =0.95); not safe (r =0.77) and feel incomplete (r =0.67).

- The following constructs have significant correlations with "feel like a person without asthma" and therefore further elaborate the negative pole of the x-axis: "content/comfortable" (r = 0.94); "unrestricted" (r = 0.91); "accepted" (r = 0.90).

(iii) Construct loadings onto Component 2

- The construct "dependent - independent" loads most significantly onto the y-axis where "independent" represents the positive pole. Independent is significantly correlated with "calm" (r = 0.69)

(iv) Element percentage sum of squares

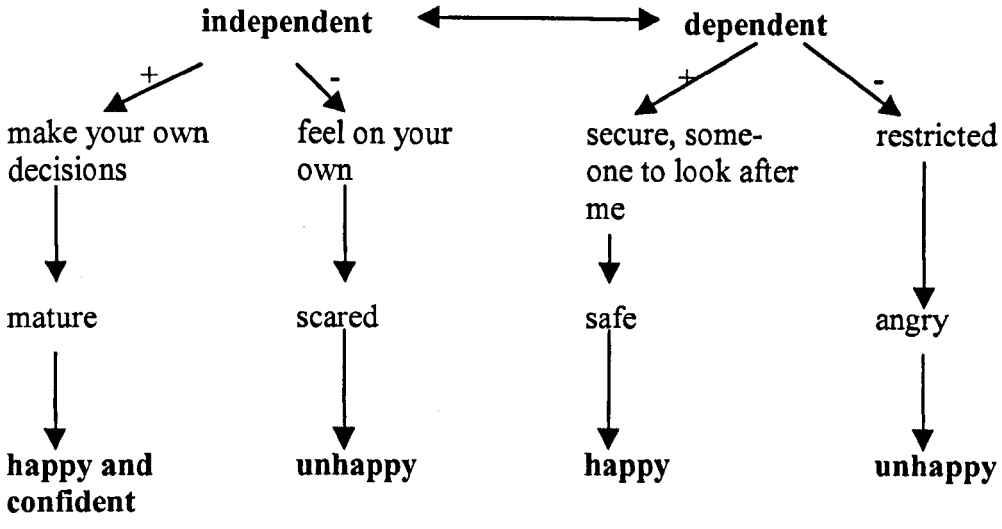
- "Me with asthma" accounts for a larger percentage variance (20.16%) compared to "me without asthma" (2.63%) or "self" (4.27%).

(v) Element interrelationships

- "Self" is rated as significantly dissimilar to "self as was" (distance = 1.44). It is not significantly associated with "ideal self".
- "Self" is rated as significantly similar to "me without asthma" (distance = 0.21) and significantly dissimilar to "me with asthma" (distance = 1.36). It is rated significantly similar to "child with asthma" (0.37).
- "Self" is rated significantly similar to "me not taking asthma medication" (distance = 0.3).
- "Self is rated as significantly similar to "as parents see me" (distance = 0.67) and "as friends see me" (distance = 0.30).
- "Self as was" is rated significantly similar to "me having asthma" (distance = 0.48) which is rated similar to "taking asthma medication" (distance = 0.67).

M.5 Laddering

"Independent – dependent" was laddered as it was identified as an ambivalent construct.



M.6 Comparison of data sources: SSI; Asthma Grid; Laddering

- The results of the SSI indicate that M doesn't perceive her asthma as problematic. This is supported by the grid as self is associated with "not having asthma". Self is associated with the element "child with asthma". This pattern of results may suggest that although asthma was not problematic at the time of the interview, she continues to identify with someone who she perceives asthmatic.
- "Self" is not associated with taking medication or forgetting to take medication, and represents an ambivalent pattern of adherence behaviour.
- The laddering of "independent – dependent" illustrates positive and negative implications to both poles of this construct. This represents an area of ambiguity within the construct system and relates particularly to the construal of asthma.