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A thesis submitted in partial fulfilment of the requirements of the  
degree of Doctor of Clinical Psychology

**Caring for Individuals with Learning  
Disabilities and Schizophrenia**

**By**

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## **Declaration**

The thesis was conducted under the academic supervision of Dr. Stephen Joseph and clinical supervision of Valerie Crowley. Dr. Stephen Joseph advised me on the development of one of the questionnaires. He also helped me to conduct the statistical analysis throughout the papers. I recruited all participants through Consultants Psychiatrists working within Learning Disability Services. Apart from the collaboration of the above people the thesis is my own work. The authorship of papers from the study will be shared with the people above. The thesis has not been submitted for a degree to any other university. Ethical approval was given by Coventry Ethics Committee and Warwickshire Ethics Committee (see Appendix A).



## Summary

This thesis is concerned with staff carers of individuals with a learning disability and a diagnosis of schizophrenia. To date this group of carers have received no attention from researchers. This is in contrast to a vast body of literature, which has established the psychological impact of care giving on the relatives of patients with a diagnosis of schizophrenia, without a learning disability. The term 'schizophrenia' has been used throughout this thesis. This reflects the use of psychiatric diagnoses in the body of research and clinical literature, which has guided the development of the current study.

The first paper critically reviews the application of attribution theory to the study of relatives' coping responses to schizophrenia and the associated symptomatology. The literature review has been prepared for submission to *Schizophrenia Bulletin* (see Appendix B for Instructions to Authors).

The brief research paper reports on the development of the Attributions for Schizophrenia Questionnaire (ASchizQ) and a preliminary investigation with staff carers of individuals with a mild learning disability and a diagnosis of schizophrenia. This paper has been prepared for submission to the *Journal of Applied Research in Intellectual Disabilities* (see Appendix C for Instructions to Authors).

The main research paper focuses on the application of attribution theory to staff caring for individuals with a mild learning disability and diagnosis of schizophrenia. It examines the relationship between staff carers' causal attributions about schizophrenia and the associated symptomatology and their current coping styles. This paper has been prepared for submission to the *British Journal of Clinical Psychology* (see Appendix D for Instructions to Authors).

Finally, the research review describes some of my experiences and observations of conducting research with carers of individuals with a mild learning disability and a diagnosis schizophrenia.

The whole thesis is less than 20,000 words (excluding references and tables).

## **Chapter One**

### **Literature Review**

# **Relatives' Response to Schizophrenia: Do Causal Attributions Matter?**

**Prepared for submission to  
Schizophrenia Bulletin**

## **ABSTRACT**

In the last three decades, a great deal of research on the families of individuals with a diagnosis of schizophrenia has concentrated on the concept of expressed emotion. This has been extensively researched and has provided strong evidence that the course and outcome of schizophrenia is highly responsive to the psychosocial environment and emotional atmosphere within the family.

Despite the wealth of research into EE, the meaning, origin and correlates of the construct remain unclear. Attribution theory has been applied to offer a theoretical framework to better understand the underlying concept of EE and its relationship to relapse, which is the focus of the current review. This review will outline attribution theory and the application and development of attributional models in schizophrenia research. The empirical studies are then presented, which provide evidence for the relationship between relatives' beliefs about the cause of schizophrenia and their coping responses. This highlights research on expressed emotion but also includes papers, which have examined other coping responses, such as psychological distress, burden and family functioning. Empirical studies, which illustrate the relationship between situational variables, relatives' causal attributions and their consequent coping responses are then presented. Finally, the research, methodological and clinical implications are discussed.

**Keywords:** Attributions, attribution theory, causal attributions, mental illness and schizophrenia.

## INTRODUCTION

Over the past three decades, a considerable body of research has focused on the expressed emotion (EE) of relatives of individuals suffering from schizophrenia. EE refers to a construct, which represents a number of key aspects of interpersonal relationships and has been described as providing a robust measure of the emotional attitude a relative shows towards a dependent person. Relatives are rated as either high or low EE depending on their ratings on measurements of criticism, hostility, emotional overinvolvement and warmth, which tend to be assessed by the Camberwell Family Interview (CFI; Vaughn and Leff 1976b).

EE has been extensively researched in the context of patients with a diagnosis of schizophrenia and their families (see Kavanagh 1992; Bebbington and Kuipers 1994; Wearden et al. 2000 for reviews) and has provided strong evidence to suggest that the course and outcome of schizophrenia is highly responsive to the psychosocial environment and emotional atmosphere within the family (Leff and Vaughn 1985). In a review of 26 studies, Kavanagh (1992) found that patients returning to hostile, critical or emotionally overinvolved environments were twice as likely to relapse within a 9-month period compared to patients returning to homes in which relatives did not express many critical or hostile attitudes. It has been suggested that the strong relationship between high EE and patient relapse may provide an index of chronic stress in the family environment, which precipitates relapse in vulnerable individuals (Barrowclough et al. 1994).

Despite the wealth of research into EE, the meaning, origin and correlates of the construct remain unclear and have yet to be understood within a broader

theoretical paradigm (Hinrichsen and Lieberman 1999). This also means that its mechanism in relapse is poorly understood (Barrowclough et al. 1994; Weisman et al. 1993). Previous literature (e.g. Leff and Vaughn 1985) conceptualised the high and low EE classification as trait-like measures. However, Barrowclough et al. (1994) highlighted the potential difficulties in adopting such a model. For example, it is unable to offer much explanation about the processes that bring about high EE attitudes in relatives or a return or exacerbation of symptoms in patients with a diagnosis of schizophrenia. It also does not allow for an explanation as to why individual relatives have different responses and attitudes to sufferers of schizophrenia or which responses might represent key stressful stimuli for relapse.

## **ATTRIBUTION THEORY**

Attribution theory has been applied to this area of research to offer a theoretical framework to better understand the concept of expressed emotion and its relationship to relapse. Attribution theory relates to causal explanations that people make to explain unusual or potentially threatening events that they observe or that happen to them in everyday life (Heider 1958). It has been suggested that people are motivated to identify the cause of such events, because they can then use the explanation to understand, control and master their difficulties (Forsterling 1988). Even though there are a vast number of causes for any event there are only a few underlying dimensions on which these can be understood (Weiner 1985). Weiner (1986) argued that it is this underlying structure, rather than the specific causes, that determines both the emotional and behavioural consequences.

The analysis of the structure of causality began with the internal-external (locus) dimension (Heider 1958). Heider (1958) proposed that causes were seen to either reside within the person (internal attribution) or were to do with other people or circumstances (external attribution). Weiner (1985) added two further dimensions, controllability and stability. Controllability refers to whether the cause is subject to personal influence or not, and stability, refers to whether the cause is perceived as temporary or permanent. Abramson et al. (1978) suggested that some causes are specific to a situation and others generalise across settings (globality-specificity). Finally, Stratton et al. (1986) proposed that some causes concern something unique or idiosyncratic about the person (personal-universal) (see Munton et al. 1999).

One of the most influential attribution theories is Weiner's (1980, 1986) attribution-affect model of helping behaviour, which suggests that different causal beliefs about other people's problems will be instrumental in producing specific emotional states. A key aspect of this model is the mediating role of affects as determinants of a person's motivated behaviour (Schmidt and Weiner 1988). Weiner (1980, 1986) demonstrated experimentally that internal, controllable attributions (e.g. lack of effort or drunkenness) led to negative affects such as anger and disgust, which resulted in negative behavioural responses, for example, avoidance, neglect and judgements about not giving help. Brewin (1988) suggested that EE researchers might classify this as a critical and/or hostile response. However, external, uncontrollable attributions (e.g. an individual's ability level or restricted opportunities) generated positive affects such as sympathy and pity and led to positive behaviours, for example, approach behaviour, support and judgements about help giving.

Weiner's (1980, 1986) attribution theory has also been used to understand relatives' emotional overinvolvement (e.g. Leff and Vaughn 1976a; Brewin et al. 1991). It has been suggested that the underlying emotional experiences of these individuals might be guilt and protectiveness. Weiner (1986) proposed that guilt is generally experienced when individuals attribute the cause of a negative event as internal and controllable to themselves. However, protectiveness might be related to experiencing pity.

Hooley (1987) also introduced an attributional model of expressed emotion, which represented a framework where a number of previously observed attributional differences between high and low EE relatives could be organised and understood (e.g. Leff and Vaughn 1976; Hooley 1985; Greenley 1986; Jenkins et al. 1986). This model suggested that high EE, particularly criticism, could be interpreted within an illness attribution and symptom controllability framework. Hooley (1987) hypothesised that high EE attitudes would develop when family members perceived that the symptoms were not the result of a legitimate illness and were to some degree controllable by the patient. These relatives might then cope by using social control methods, such as nagging, criticising or coercing the patient in an effort to modify undesirable behaviour, which in turn was hypothesised to contribute towards a higher probability of relapse. On the other hand, low EE relatives were hypothesised not to hold patients responsible for their behaviour, as it would be perceived as an inevitable side effect of a genuine illness. These relatives were thought to respond to the symptoms of schizophrenia with greater patience, understanding and a tolerant, non-intrusive approach to coping, which in turn was thought to contribute to less stress and a more favourable outcome.

Leff and Vaughn (1985) presented a slightly different hypothesis. They suggested that many relatives would already be aware that the patient had received a psychiatric diagnosis and may occupy a “sick role” (Parsons 1951). Therefore, an illness conceptualisation might imply that the person’s behaviour is not all under their control and therefore, personal responsibility might be diminished. If this were the case then attributions of controllability might not play a central role in the context of caring for a person with a diagnosis of schizophrenia, as they did in the student populations in which attribution theory was developed (see Weiner 1980). They suggested that relatives who questioned or denied that the patient was truly ill, might perceive the cause of the negative behaviours to reflect the patients’ enduring personality characteristics and idiosyncrasies (internal attribution). This might then lead to the use of combative or intrusive efforts to make patients change.

## **EMPIRICAL STUDIES**

PsychInfo and Medline were used to conduct a systematic search of the research literature using the keywords ‘attributions’, ‘attribution theory’, ‘causal attributions’, ‘mental illness’ and ‘schizophrenia’. This was undertaken to identify empirical studies, which have applied attribution theory to study the relationship between relatives’ attributions about the cause of schizophrenia and their coping responses. This was also augmented by additional citations obtained from journal articles and includes articles published between 1987 and 2001. These articles are reported in Table 1 (below). Table 1 provides detailed information about each article, which is in addition to that reported in the text. This includes the research design and participants, the variables used in each study and the major findings.



**Table 1. Summary of Empirical Studies**

STUDY	RESEARCH DESIGN AND PARTICIPANTS	VARIABLES INCLUDED IN STUDIES	MAJOR FINDINGS
Barrowclough et al. (1996)	Cross-sectional. n = 60 relatives of 51 patients recruited during an acute episode of schizophrenia. Data was analysed using Mann Whitney U tests, correlations and multiple regression.	Frequency of hospital admission and duration of illness. Camberwell Family Interview (CFI; Vaughn and Leff 1976b). Spontaneous causal attributions – The Leeds Attributional Coding System (LACS; Stratton et al. 1986). Attributional dimensions - internal-external, personal-universal, controllable-uncontrollable and stable-unstable (patient) and internal-external and controllable-uncontrollable (relative). General Health Questionnaire 60-item (GHQ-60; Goldberg and Williams 1988).	Relative's self-blaming beliefs were associated with their distress. Distress was unrelated to relative's beliefs about the patient's role in negative events.
Barrowclough et al. (1994)	Longitudinal. n = 60 relatives and 51 patients with a diagnosis of schizophrenia recruited during an admission to an acute ward. Data was analysed using Chi-squared tests, Mann Whitney U tests, analysis of variance, correlations, partial correlations and multivariate analysis.	Camberwell Family Interview (CFI; Vaughn and Leff 1976b). Spontaneous causal attributions – The Leeds Attributional Coding System (LACS; Stratton et al. 1986). Attributional dimensions - internal-external, personal-universal, controllable-uncontrollable and stable-unstable (patient) and internal-external and controllable-uncontrollable (relative). Psychiatric Assessment Scale (PAS; Krawiecka et al. 1977). Present State Examination (PSE; Wing et al. 1974). Family Questionnaire (FQ; Barrowclough and Tarrrier 1992).	High EE relatives made more attributions about illness than did low EE relatives. Relatives with marked emotional overinvolvement were similar to the low EE group, with problems attributed to factors more external to and uncontrollable by the patient. Relatives with high criticism gave more causes internal to the patient. Hostile relatives tended to perceive the causes to be controllable by and personal to the sufferers of schizophrenia. Illness chronicity and severity was associated with more causal search. Attributional variables were better predictors of patient relapse at nine-months than were EE measures.
Bentsen et al. (1997)	Partly cross-sectional, partly longitudinal. n = 70 relatives of 47 patients with a diagnosis of schizophrenia and schizophreniform disorder admitted to a psychiatric hospital because of an acute episode. Data was analysed using multiple regression.	Locus of Control (LOC) - Internality, Powerful Others and Chance (IPC) scales (Levenson 1973, 1974). General Health Questionnaire 30-item version (GHQ-30; Goldberg and Williams 1988). Expressed Emotion - Camberwell Family Interview (CFI; Vaughn and Leff 1976b).	Chance LOC was positively related to emotional overinvolvement. Powerful others LOC, especially 'wish to ingratiate' items, were positively linked to criticism and, among workers/lower grade employees only, to emotional overinvolvement. Internal LOC was not linked to EE scale.

Brewin (1994)	Cross-sectional. n = 26 relatives of patients with a diagnosis of schizophrenia. Data was analysed using analysis of variance.	Camberwell Family Interview (CFI; Vaughn and Leff 1976b). Spontaneous causal attributions - The Leeds Attributional Coding System (LACS; Stratton et al. 1986). Attributional dimensions - stable-unstable, global-specific, internal-external, personal-universal and controllable-uncontrollable (patient). An index of disturbed behaviour was derived from relatives' answers to standardised questions on the Camberwell Family Interview.	There was a general reduction in relatives' criticism and hostility, a shift towards making more universal attributions for patients' negative behaviours and more use of attributions to illness. Reductions in criticism were not related to attributional change, but reductions in hostility were associated with a shift towards more universal and uncontrollable attributions.
Brewin et al. (1991)	Cross-sectional. n = 58 relatives of 49 patients with a diagnosis of schizophrenia (21 patients had first onset of schizophrenia within the last 12 months). Data was analysed using correlation and analysis of variance.	Camberwell Family Interview (CFI; Vaughn and Leff 1976b). Spontaneous causal attributions - The Leeds Attributional Coding System (LACS; Stratton et al. 1986). Attributional dimensions - stable-unstable, global-specific, internal-external, personal-universal and controllable-uncontrollable (patient) and internal-external and controllable-uncontrollable (relative). An index of disturbed behaviour was derived from relatives' answers to standardised questions on the Camberwell Family Interview.	Relatives made predominantly internal, universal and uncontrollable about the patient and external, universal, and uncontrollable about themselves. Low EE relatives' attributions were similar to the emotionally overinvolved relatives. Critical and/or hostile relatives made more attributions to factors personal to and controllable by the patient. Hostile relatives made more internal attributions to the patient and by making attributions with fewer causal elements.
Harrison and Dadds (1992)	Cross-sectional. n = 31 caregivers of patients with a diagnosis of schizophrenia (chronic). Data was analysed using analysis of variance, comparison tests and correlations.	Structured interview schedule included: Knowledge about the diagnosis and illness (four questions). Causal attributions about 28 symptoms - measuring attributions about control, illness, personality, or other factor. Five Minute Speech Sample (FMSS; Magana et al. 1986). Coping - general/past month - 1-5 likert scale. Social interaction - number of outings and number of visitors in past week - enjoyability rating for each. The General Health Questionnaire (GHQ-28; Goldberg 1972).	EE status was related to knowledge, coping and causal attributions of negative symptoms. Low EE, as compared with high EE caregivers, tended to have more knowledge of the illness, to cope better and were less likely to attribute the cause of the negative symptoms to the sufferer's personality.
Harrison et al. (1998)	Cross-sectional. n = 84 caregivers of patients with a diagnosis of schizophrenia. Data was analysed using hierarchical multiple regression.	Knowledge of illness (developed for the study). Attributions of Symptoms Inventory (Harrison and Dadds 1992). Five Minute Speech Sample (FMSS; Magana et al. 1986).	Three variables significantly predicted caregivers' criticism of the patient; a smaller proportion of negative symptoms in the patient's overall symptom pattern, the caregiver's low level of knowledge, and attributing the cause of the negative symptoms to the patient's personality rather than to the illness.

<p>Hinrichsen and Lieberman (1999)</p>	<p>Cross-sectional.  <math>n = 63</math> family members of patients with a first episode of schizophrenia or schizoaffective disorder.  Data was analysed using hierarchical multiple regression.</p>	<p>The Psychiatric Disabilities Attribution Questionnaire (Krauss 1989) - measuring psychogenic, moral, organic and stress attributions about the cause of psychiatric illness.  Health and Daily Living Form - Indices of Coping (Moos et al. 1984).  Dementia Management Strategies Scale (Hinrichsen and Niedererhe 1994).  Patient Rejection Scale (Expanded version) (Kreisman et al. 1988).  The Burden Interview (Zarit and Zarit 1983).  The Symptom Checklist-90 (SCL-90; Derogatis et al. 1973).</p>	<p>Family members showed evidence of reasonably good emotional adjustment.  Poorer emotional adjustment was linked to (i) attributions that were more likely to place responsibility for psychiatric illness on the patient, and moral and psychogenic causes were linked to higher levels of patient rejection, (ii) coping that was avoidant and (iii) patient management strategies that involved conflict avoidance and authoritarianism/reasoning.</p>
<p>Hooley (1998)</p>	<p>Cross-sectional.  <math>n = 65</math> relatives of 45 patients with a diagnosis of schizophrenia, schizoaffective disorder, or psychotic disorder not otherwise specified during inpatient hospitalisation.  Data was analysed using correlations and analyses of variance.</p>	<p>Camberwell Family Interview (CFI; Vaughn and Leff 1976b).  Locus of Control Behaviour Scale (LCB; Craig et al. 1984).</p>	<p>Relative to the general population highly critical relatives had a more internal locus of control whereas low critical relatives had a more external locus of control.  The attributions and beliefs about control, which characterise critical relatives when they are speaking about the patient, may also reflect attributions and beliefs that relatives hold for themselves.  Critical comments were strongly correlated with active coping with problems or the management of physical symptoms. Low criticism was correlated with agreeing more strongly with remarks such as 'it is impossible to control my irregular and fast breathing when I am having difficulties'.</p>
<p>Hooley et al. (1987)</p>	<p>Cross-sectional.  <math>n =</math> varied - married couples with a partner with a diagnosis of schizophrenia, unipolar depression, or bipolar disorder.  Data was analysed using correlations, chi squared, analysis of variance and hierarchical multiple regression.</p>	<p>Current and Past Psychopathology Scales (CAPPS; Endicott and Spitzer 1972).  Marital Adjustment Test (MAT; Locke and Wallace 1959).</p>	<p>Spouses of patients with negative symptoms and impulse-control deficits reported significantly lower levels of marital satisfaction than spouses of patients with positive symptoms.</p>

<p>López et al. (1999)</p>	<p>Cross-sectional.  n = 40 key relatives of 40 patients with a diagnosis of schizophrenia, who had been hospitalised one month prior to initial interview. Patients did not include individuals with unchanging or persisting symptoms.  Data was analysed using correlations.</p>	<p>Camberwell Family Interview (CFI; Leff and Vaughn 1976b).  Attributions of Controllability – one rating on a 5-point likert scale (1 = no perceived control, 5 = perceived control over all aspects of the disorder).</p>	<p>Non-EOI family members' attributions of control correlated positively with patient outcome measures and families' level of criticism correlated negatively with families' degree of warmth. Criticism but not warmth was associated with relapse. Partial support was found for an attribution-emotion model of relapse, one in which attributions and emotion (criticism) jointly predict clinical outcome. Patients' illicit use of street drugs was interrelated with families' attributions and criticism in predicting clinical outcome.</p>
<p>Medvene and Krauss (1989)</p>	<p>Cross-sectional.  n = 57 group members of psychiatrically disabled adult children (National Alliance for the Mentally Ill).  Data was analysed using principle component factor analysis and analysis of variance.</p>	<p>Semi-structured interviews led to the development of a 113-item questionnaire, including items on parents' thoughts and feelings regarding the causes of their offspring's problems and their relationships with their disabled offspring, attendance and participation at the AMI meetings, family burden, contact with professionals, group environment and demographic characteristics. The Psychiatric Disabilities Attribution Questionnaire (Krauss 1989), measuring psychogenic, moral and organic attributions about the cause of psychiatric illness. Index of behavioural interactions. Index of Participation. Index of Homogeneity</p>	<p>Parents endorsed psychogenic, organic and moral causes about their offspring's' psychiatric disabilities. Parents' attributional processes were influenced by their organisational participation. Comparatively stronger endorsement of the organic attribution and comparatively weaker endorsement of the psychogenic attribution tended to be associated with participation. Increased comfort in the parent-child relationship was also associated with participation.</p>
<p>Natale and Barron (1994)</p>	<p>Cross-sectional.  n = 33 mothers who were the primary care givers to a son with a diagnosis of schizophrenia. The average patient had been diagnosed for 8 years (SD = 5.45).  Data was analysed using content analysis (causal attributions) and correlations.</p>	<p>Causal Dimension Scale (Russell 1982) – measuring internal, controllable (mother) and stable (schizophrenia) attributions. Short form of the Multiscore Depression Inventory (SMDI; Berndt et al. 1984).</p>	<p>Mothers generated 50 causal explanations for their son's schizophrenia. The most frequently cited causal category was physiological/biological factors. Guilt was associated with causal explanations characterised as internal, whereas depression was unrelated to causal dimensions.</p>

<p>Provencher and Mueser (1997)</p>	<p>Cross-sectional. n = 70 primary caregivers of persons with a diagnosis of schizophrenia or schizoaffective disorder. Data was analysed using correlations.</p>	<p>The Behavioural Disturbance Scale (BDS), the Objective Burden Questionnaire (OBQ) and the Subjective Burden Scale (SBS) – modified versions of scales included in the Social Behavioral Assessment Schedule (SBAS; Platt et al. 1983). The Responsibility Attribution Scale (RAS; Drown 1986) – measuring responsibility attributions for eight positive and eight negative symptom behaviours.</p>	<p>Subjective burden was related to both the severity of positive and negative symptom behaviours, whereas objective burden was related only to the severity of negative symptom behaviours. Responsibility attribution for negative symptom behaviours was only related to objective burden. This remained significant after controlling for the severity of negative symptoms. Caregivers who perceived their relative as less responsible for negative symptom behaviours reported higher levels of objective burden. Caregiver's perceptions of responsibility for positive symptom behaviours were not related to objective or subjective burden.</p>
<p>Robinson (1996)</p>	<p>Cross-sectional. n = 78 family members of a relative who was mentally ill, with a diagnosis of schizophrenia (15), schizoaffective (11), bipolar affective (7), schizophreniform (3) and depressive (2) disorders. Data was analysed using t-tests and correlations.</p>	<p>The General Functioning Scale (GFS) of the Family Assessment Device (FAD; Epstein et al. 1983). Causal attributions were measured by an adapted instrument used by Downey et al. (1990), which comprised an initial open-ended question 'At this time, why do you think (your son/daughter/brother/sister/you) became ill?' Followed by eight closed questions about the extent to which eight causal agents were responsible for the illness (client, parents, other family members, heredity, biology, someone outside the family, God and chance).</p>	<p>Poor family functioning was associated with making attributions to a person as the cause of the illness. No relationship was found between family functioning and causal attributions to genetics, biology, chance or fate.</p>
<p>Weisman (2000)</p>	<p>Experimental and cross-sectional. n = 88 Mexican and 88 Anglo-American undergraduate psychology students. Data was analysed using regression.</p>	<p>Two vignettes were designed, one to meet the criteria for positive symptoms and the other to meet the criteria for negative symptoms of schizophrenia, as described in the DSM-IV. Causal attributions about the vignettes were measured by an adapted version of the Causal Controllability Scale (Russell 1982) - controllability, intentionality and responsibility of the patient on 9-point likert scales. Moral-Religious Emphasis Subscale of the Family Environment Scale (FES; Moos and Moos 1981)</p>	<p>Greater religiosity was positively correlated with increasing perceptions of control over the symptoms of schizophrenia, which stemmed from the premise that religious individuals may be more likely to perceive another's adversity (such as having schizophrenia) as punishment for prior wrongdoings or for failure to try to help oneself.</p>
<p>Weisman and López (1997)</p>	<p>Experimental design. n = 88 Mexican and 88 Anglo American undergraduate psychology students. Data was analysed using correlations and ANOVAS.</p>	<p>Two vignettes were designed, one to meet the criteria for positive symptoms and the other to meet the criteria for negative symptoms of schizophrenia, as described in the DSM-IV. Causal attributions about the vignettes and specific symptomatic behaviours extracted from the vignettes were measured by an adapted version of the Causal Controllability Scale (Russell 1982) - controllability, intentionality and responsibility about the patient on 9-point likert scales. Five favourable and five unfavourable affects were measured on 9-point likert scales.</p>	<p>Negative symptoms were associated with greater perceived control than positive symptoms. Negative symptoms were associated with more intense negative affect and less intense positive affect than positive symptoms. Some nationality and gender differences were found.</p>

<p>Weisman et al. (1993)</p>	<p>Cross-sectional n = 46 key family members of patients with a diagnosis of schizophrenia (Mexican American). Data was analysed using ANOVA, t-tests and correlations.</p>	<p>The Camberwell Family Interview (Leff and Vaughn 1976b). Attributions of Controllability – one rating on a 5-point likert scale (1 = no perceived control, 5 = perceived control over all aspects of the disorder). Positive and negative affect – one rating on a 10-point likert scale (0 = very negative and 10 = very positive).</p>	<p>High EE families had significantly higher controllability ratings than low EE relatives. This is consistent with the hypothesis that high EE relatives would view the illness and associated symptoms as residing within the patient's personal control, more than low EE families. Family members attributions were related to their affective responses. Family members who perceived the patient as having control over the symptoms of schizophrenia tended to express greater negative emotions, e.g. anger and annoyance, than family members who viewed the symptoms as beyond the patient's personal control. The authors suggest that the attributional model may have cross-cultural relevance in understanding the EE construct.</p>
<p>Weisman et al. (2000)</p>	<p>Cross-sectional. n = 35 Anglo-American family members of patients with a diagnosis of schizophrenia or schizoaffective disorder. The patients had an initial onset of psychosis not more than two years before entry into the project. Data was analysed using regression.</p>	<p>The Camberwell Family Interview (CFI; Leff and Vaughn 1976b). The content of critical comments was evaluated and classified into one of seven categories (negative symptoms, positive symptoms, antisocial behaviours, substance abuse, other symptoms, enduring personality traits, and other nonsymptomatic behaviours). Attributions of Controllability – one rating on a 5-point likert scale (1 = no perceived control, 5 = perceived control over all aspects of the disorder).</p>	<p>High EE relatives had a strong tendency to attribute more control over behaviour to patients than do low EE relatives of the same patient. Low EE relatives from high EE homes perceived the patient to have more control over the disorder and the disruptive symptoms than did low EE relatives from low EE homes. High EE relatives from high EE homes were found to make more critical comments for negative symptoms, enduring personality traits and other, non-symptomatic behaviours compared with low EE relatives from high EE homes.</p>
<p>Weisman et al. (1998)</p>	<p>Cross-sectional. n = 40 Anglo American family members with a family member with either a diagnosis of schizophrenia or schizoaffective disorder. Initial onset of psychosis not more than 2 years before project entry. Data was analysed using t-tests.</p>	<p>The Camberwell Family Interview (CFI; Leff and Vaughn 1976b). The content of critical comments was evaluated and classified into one of seven categories (negative symptoms, positive symptoms, antisocial behaviours, substance abuse, other symptoms, enduring personality traits, and other nonsymptomatic behaviours). Attributions of Controllability – one rating on a 5-point likert scale (1 = no perceived control, 5 = perceived control over all aspects of the disorder). Brief Psychiatric Rating Scale (BPRS) was used to assess the severity of patients' positive and negative symptoms.</p>	<p>The results replicate and lend cross-cultural support to Weisman, López et al.'s (1993) study. Highly critical relatives viewed the illness and associated symptoms as residing more within the patient's personal control compared with less critical relatives (low EE). Negative symptoms were criticised more often than positive symptoms. High EE relatives criticised negative symptoms more frequently than did low EE relatives. Patients' from these relatives did not have more severe negative symptoms. High EE relatives complained more about longstanding personality characteristics and nonsymptomatic behaviour than low EE relatives.</p>

## **ATTRIBUTIONS AND EXPRESSED EMOTION**

A number of research groups have applied either Weiner's (1980, 1986) or Hooley's (1987) attributional model to the construct of EE, which has provided empirical evidence that relatives' beliefs about the cause of schizophrenia and associated symptomatology can help to explain the differing responses that they make towards their relatives' illness. These papers will be summarised below. Barrowclough et al. (1996) have also stated that this work has helped to shift thinking away from the idea of EE being a simple, somewhat blameworthy trait-like response to the patient at the time of acute illness and crisis.

### **Attributions and High EE (Criticism/Hostility)**

Brewin et al. (1991) were one of the first groups to test the utility of Weiner's (1980, 1986) attributional model to 58 relatives of patients with a diagnosis of schizophrenia. They found that hostile relatives made causal attributions that were more internal, personal and controllable by the patient, such as laziness or a desire to provoke or confront, whereas criticism was associated with causal factors that were more personal and controllable but not necessarily more internal to the patient. They concluded that the relationship between attributions and relatives' criticism and hostility was in line with Weiner's (1986) attributional theory of emotion, with hostility appearing to follow the pattern predicted by Weiner (1986) for anger.

Barrowclough et al. (1994) examined 60 relatives of patients with a diagnosis of schizophrenia and found slightly different results. Critical relatives made more internal attributions to the patient, whereas hostile relatives tended to perceive the causes to be more controllable by and more personal to the sufferer of

schizophrenia. Both research groups used the CFI as source material to elicit relatives' spontaneous causal attributions about schizophrenia. However, Barrowclough et al. (1994) modified Brewin et al.'s (1991) guidelines for identifying, measuring and coding causal attributions due to the reported difficulties attaining consistency between raters from verbatim interviews (Stratton et al. 1986). Therefore, this might explain the differences in the results found between the two studies.

A different research group (e.g. Weisman et al. 1993; Weisman and López 1997; Weisman et al. 1998) have applied Hooley's (1987) model of expressed emotion to examine the relationship between relatives' beliefs about patients' volitional control over schizophrenia and associated symptomatology and their level of expressed emotion. Their findings are consistent with previous findings (e.g. Brewin et al. 1991; Barrowclough et al. 1994). High EE relatives (criticism) had significantly higher ratings of controllability than low EE relatives. They concluded that excessive perceptions of control might be harmful in the course of schizophrenia, rather than the perception that their relatives may have some control over their illness. Therefore, they suggested that families who cope well with their disturbed relatives behaviour may be those who maintain a delicate balance between perceiving some control whilst recognising that some of the odd or disruptive behaviour is an inevitable side effect of a genuine illness. However, it is not possible to generalise these results to emotionally overinvolved or hostile relatives because controllability attributions were only measured in relationship to relatives' criticism.

In addition to EE, Weisman et al. (1993) and Weisman and López (1997) also included measures of relatives' positive and negative affect to test Weiner's (1986) attribution model more directly. Weisman et al. (1993) found that the



more relatives viewed the patient as having control over his or her behaviour, the more they expressed negative affect such as anger and annoyance towards their ill relative. Weisman and López (1997) found slightly different results. The more participants perceived the cause and symptoms of the disorder as controllable, the less they expressed favourable affect towards the patient. Contrary to Weiner's (1980, 1986) model, unfavourable affect was not associated with controllability attributions. However, participants in this study were students. Therefore, the artificial nature of the analogue study might have failed to capture the negative emotion that might be experienced by family members living with a relative with a diagnosis of schizophrenia.

### **Attributions and High EE (Emotional Overinvolvement)**

Much of the empirical literature has focused on the relationships between controllability attributions and criticism. This is because criticism is the element of EE, which has been found to contribute most to the correlation between EE and relapse (Hooley 1998). However, although emotional overinvolvement has been associated with a significant degree of relapse relatively few studies have applied an attributional model to these relatives. Those that have (e.g. Brewin et al. 1991; Barrowclough et al. 1994; Harrison and Dadds 1992), report very similar results. The attributions of EOI relatives' were found to be similar to those reported by low-EE relatives, who made the most universal, least controllable and least internal attributions.

Barrowclough et al. (1994) proposed that different attributional dimensions might mediate different coping responses found between high EE relatives (criticism, hostility and emotionally overinvolvement). For example, internal, controllable attributions might result in efforts to persuade or coerce the patient to improve or

restore his/her behaviour back to pre-illness levels or to behave normally (a critical/hostile attitude). This type of coping might be stressful for the vulnerable patient with a diagnosis of schizophrenia and consequently lead to relapse. On the other hand, external, uncontrollable attributions might result in relatives attempting to improve events by using themselves as a buffer between the patient and the outside world by taking control and doing things for the patient (self-sacrificing and intrusive behaviours). This might not represent increased stress but may serve to maintain symptoms. Therefore, Brewin et al. (1991) and Barrowclough et al. (1994) have suggested that an attributional model of relapse might not apply to EOI households. They proposed that it might be more important to study family members' behavioural interactions with their ill relatives, alongside their attributions and affective responses, in order to better understand the relationship between family factors and clinical course in this group.

### **Attributions and Low EE (Warmth)**

There have also been very few studies, which have examined the relationship between relatives' attributions and positive coping responses, such as warmth (low EE). This is despite the fact that most families adapt to the stressors and manage to care effectively for their relative (e.g. Barrowclough et al. 1994; Lopez et al. 1999; Robinson 1996). However, López et al. (1999) have tested a complete attributional model of relapse with 40 key relatives of patients with a diagnosis of schizophrenia, in order to begin to determine which family factors might be protective against relapse. They examined the relationship between relatives' attributions and their prosocial (warmth) and asocial (criticism) responses to the patients' clinical outcome. Their findings were consistent with previous research. They found that the more family members viewed ill relatives

as having control over their symptoms and behaviour, the less they expressed positive affect and the more they expressed negative affect. Barrowclough et al.'s (1994) findings were also consistent with this study. They found that more warmth expressed by family members was associated with less volitional control that they judged their relative to have.

The results across the studies reported above are mixed, which is perhaps due to the application of different attributional models, methodologies and attributional dimensions. However, one consistent finding concerns the dimension of control and its differences between high and low EE relatives. High EE relatives tend to make more controllable attributions than their low EE counterparts.

### **RELATIVES' LOCUS OF CONTROL AND EXPRESSED EMOTION**

A separate line of research has proposed that relatives locus of control (LOC) might influence their EE. LOC is a generalised expectancy related to the connection between personality characteristics and experienced outcomes (see Bentsen et al. 1997). This research has drawn on earlier observational findings (e.g. Hooley 1985, 1987; Greenley 1986), which indicated that high EE might be viewed as intense attempts to control the patients' behaviour. Hooley (1985) suggested that the likelihood of such attempts might be linked to relatives' generalised expectancies of control.

Bentsen et al. (1997) studied 70 relatives of individuals with a diagnosis of schizophrenia or schizophreniform disorder. They found a strong positive relationship between the Chance Locus of Control (LOC) and EOI. They suggested that the more relatives' perceived their own lives to be unpredictable

the greater the likelihood that they may attempt to cope by preventing the patient from being exposed to unfamiliar situations (overprotecting behaviour). They also found that a low score on the Powerful Others LOC scale was significantly related to making fewer critical comments. Bentsen et al. (1997) proposed that relatives who do not care about complying with the wishes of others would be less inclined to be critical towards their relative with a diagnosis of schizophrenia. The authors also predicted that relatives who believe in their own efficacy might expect that the patient would also influence his or her own life to some degree. Contrary to the hypotheses, no significant differences were found between Internal LOC scores and relatives' criticism and hostility. However, the authors suggested that this might be due to the deficient psychometric properties of the Internal LOC scale in this population.

Using a different methodology, Hooley (1998) examined 65 relatives' of patients with a diagnosis of schizophrenia, schizoaffective disorder, or psychotic disorder not otherwise specified. Hooley (1998) studied relatives' beliefs about their own ability to control problem situations and their level of expressed emotion. In contrast to Bentsen et al.'s (1997) study, Hooley (1998) did find that high-critical relatives had a more internal locus of control than low-critical relatives. However, the high EE relatives' internal locus of control was found to be similar to that of the general population, which is seen to reflect an active, resourceful approach to coping and emphasises personal accountability. Therefore, Hooley (1998) suggested that criticism seemed to be associated with a positive, rather than a negative characteristic in relatives. Hooley (1998) hypothesised that relatives who believe that they are capable of controlling their own personal problems may be more inclined to make causal attributions that assume that others can or should be able to do the same. Despite only two studies in this field, the results

provide some evidence that relatives' locus of control might influence their coping responses towards their relative's illness.

## **ATTRIBUTIONS AND NON-EE RESPONSES**

Research clearly demonstrates that relatives can experience a considerable amount of stress and burden as a consequence of the illness (e.g. Fadden et al. 1987; Bland 1989). Surveys of family group members of the National Alliance for Mentally Ill (NAMI) (Hatfield 1978; Spaniol et al. 1985) have also documented that some relatives' experience strong feelings of guilt and stigma and may make self-blaming attributions about the cause of schizophrenia. There have been five studies, which have drawn on attribution theory to examine the relationship between relatives' causal attributions and a broader range of coping responses other than EE, including psychological distress, burden and family functioning. These studies will be highlighted below.

Natale and Barron (1994) studied 33 mothers whose sons had been diagnosed with schizophrenia. They examined the relationship between mothers' causal explanations for their sons' schizophrenia and their level of depression and guilt. The results indicated that guilt was associated with mothers' internal attributions but not with controllable or stable attributions. Depression was not found to be associated with any of the attributional dimensions. A limitation of this study was that it focused on the cause of schizophrenia itself, which had begun on average, eight years previously. However, attribution research generally investigates recent and time limited events (Weiner 1986). Therefore, the lack of relationship between these variables might have been caused by the nature of the event examined.

Barrowclough et al. (1996) studied the beliefs about schizophrenia and psychological distress of 60 relatives' of patients during an acute episode of the illness. They found a lack of association between relatives' distress and attributions to the patients' causality. However, their results were similar to those reported by Natale and Baron (1994). They concluded that relatives' emotional adjustment was related to illness events, which were perceived as being caused by factors, which were predominantly internal to the relatives themselves. This was regardless of the amount of control the relative perceived themselves to have over the problems.

Robinson (1996) studied 78 family members of chronically mentally ill patients. This study investigated whether attributions to factors within the family, for example, self-blame or blaming the client or another family member, would be associated with negative family functioning. While, attributions to causes outside the family, for example, biology, heredity, individuals outside the family, fate or God, would be associated with positive family functioning. The results indicated that the mean family attribution to causes within the family was associated with poor family functioning. However, there was no significant association between attributions to causes outside the family and family functioning. Robinson (1996) also found that people-based causal attributions were associated with poorer family functioning. This meant that family members who blamed people for the illness saw their families as less caring, cohesive or able to solve problems or communicate, compared to those who did not blame people. The opposite did not appear to be the case. Causal attributions to nonhuman agents (biology, heredity, God or chance) were not associated with positive family functioning. Additional qualitative data on people-based attributions suggested an association with anger, resentment, guilt or bitterness. Robinson (1996) proposed that these feelings might undermine interpersonal relationships within

the family, thereby challenging the functioning of the family as a coherent and supportive social unit.

Provencher and Mueser (1997) studied 70 primary caregivers of patients with a diagnosis of schizophrenia or schizoaffective disorder. They investigated the relationship of perceived severity and responsibility attributions for positive and negative symptom behaviours to caregiver burden. Contrary to the hypotheses, caregivers who perceived their ill relative as less responsible for negative symptom behaviours reported significantly greater levels of objective but not subjective burden. They found that caregivers tended to make low levels of responsibility attributions for both positive and negative symptom behaviours and suggested that relatives might perceive the main cause of these symptoms to be a biological illness. They hypothesised that a negative consequence of attributing a sick-role to the patient (Parsons 1951) might involve believing that the patient is incapable of altering any of their negative symptom behaviours. Caregivers may then take on extra responsibilities themselves, which might result in an increase in objective burden.

Finally, Hinrichsen and Lieberman (1999) examined 63 family members' emotional adjustment to caring for a patient with a first episode of schizophrenia or schizoaffective disorder. They found that attributions that were more likely to place responsibility for the psychiatric illness on the patient (psychogenic and moral causes) were linked to higher levels of patient rejection. These findings appear to be similar to studies, which have demonstrated a relationship between internal, controllable and personal attributions to the patient and high EE in relatives (e.g. Brewin et al. 1991; Weisman et al. 1993; Barrowclough et al. 1994). They also found that organic, psychogenic and moral attributions were all significantly related to greater levels of burden, which seem to parallel

Provencher and Mueser's (1997) findings. They suggested that although an organic attribution might for some patients absolve them of any personal blame for psychiatric problems, the family member is still burdened with the unfavourable implications of this attribution both for the patient and family member.

It is difficult to draw too many conclusions due to the small number of studies, which report different types of attributional dimensions and coping responses. However, the findings do appear to provide further support for the importance of attributional processes in family carers' psychological adjustment to their relatives' illness.

## **SITUATIONAL FACTORS AND ATTRIBUTIONS**

Relatives EE status had previously been thought to be independent of patient characteristics. This was due to the fact that earlier studies reported no significant differences between EE ratings and either the patients' symptomatology or their premorbid levels of functioning, such as their educational level or age of onset of first psychotic episode (e.g. Nuechterlein et al. 1986; Goldstein et al. 1989). However, because of research linking relatives' causal attributions to their EE status, a number of empirical studies have been undertaken, which begin to explore the relationship between a number of situational variables, relatives' causal attributions and their subsequent coping responses. These studies, which will be highlighted below, have included, type of symptom, enduring personality traits, gender of the relative and patient, knowledge about the illness and cultural differences.



## Symptom Type

Hooley (1987) suggested that relatives of psychiatric patients might have difficulties deciding if the patients behaviour was illness-related or under the patients volitional control. Hooley (1987) hypothesised that relatives might attribute behavioural deficits (e.g. negative symptoms) to the patient's volitional control because most of these individuals would have exhibited relatively normal levels of such behaviour in the past. Therefore, these symptoms would be attributed to aspects of the patients' personality, such as their unwillingness to engage in appropriate behaviours, rather than to the 'illness'. It was also suggested that deficits in impulse control (e.g. alcohol abuse and antisocial behaviour) might be attributed in a similar way because these difficulties would also be unlikely to be perceived as illness-related. However, in contrast, Hooley (1987) hypothesised that the florid and unusual nature of positive symptoms (e.g. hallucinations and delusions) might be perceived as unintentional and involuntary. Therefore, it might be easier for relatives to attribute these types of symptoms to a genuine illness.

Hooley et al. (1987) applied this symptom controllability model to the level of marital satisfaction amongst spouses of patients with a diagnosis of schizophrenia or an affective disorder. They found that spouses of patients with negative symptoms and impulse-control deficits did report significantly lower levels of marital satisfaction than spouses of patients with positive symptoms. However, the study only indirectly tested the model. The authors did not directly elicit spouses' perception of the controllability of their partners' symptoms. Therefore, the results only provided tentative support for the model.

A number of research groups have now provided further support for Hooley's (1987) model (e.g. Brewin et al. 1991; Barrowclough et al. 1994; Weisman and López 1997; Weisman et al. 1998; Weisman et al. 2000; Harrison and Dadds 1992; Harrison et al. 1998). Brewin et al. (1991) found that antisocial behaviour and negative symptoms were perceived as more controllable than the illness itself. Barrowclough et al.'s (1994) findings indicated that negative interpersonal problems had more internal, personal and stable attributions compared with avolition or apathy. They hypothesised that relatives might have significantly more difficulty attributing these types of behaviours to illness factors or to other universal and external causes. However, contrary to Hooley's (1987) hypothesis, Barrowclough et al. (1994) found a trend for positive symptoms to be attributed to personal causes, which suggested that relatives did not view delusion or hallucination related behaviours as illness factors.

Harrison and Dadds (1992) studied 31 caregivers of patients with a diagnosis of schizophrenia, whose condition was described as chronic. The findings provided partial support for Hooley's (1987) model. They did not find a significant difference between the perceived controllability of either positive or negative symptoms. However, there was some evidence to suggest that positive symptoms were more likely to be attributed to illness factors than negative symptoms. In a further study of 84 carers of patients with a diagnosis of schizophrenia, Harrison et al. (1998) found that a critical response was associated with a smaller proportion of negative symptoms. They suggested that when a patient has a large number of positive symptoms, a small number of negative symptoms are more likely to be viewed as part of the patients' personality and therefore under the patients control.

Weisman and López' (1997) studied 88 Mexican and 88 Anglo-American students and concluded that symptom type was a critical factor in shaping attributions and emotional reactions towards patients. They found that patients characterised by positive symptoms, which were perceived as less controllable than negative symptoms, were responded to with more intense positive emotion than patients who were characterised by negative symptoms. On the other hand, negative symptoms, which were perceived as more controllable by the patient, were responded to with more unfavourable affect. These findings were in line with Weiner's (1980, 1986) attribution theory.

Weisman et al. (1998) also studied 40 Anglo-American family members of patients with a diagnosis of schizophrenia. They found that high EE relatives frequently made more criticisms about enduring personality traits, negative symptoms and other non-symptomatic behaviours than low EE relatives, which provided indirect support for Hooley's (1987) model. Weisman et al. (2000) extended this study to 35 pairs of Anglo-American family members of patients with a diagnosis of schizophrenia or schizoaffective disorder. They hypothesised that if differences in patients' behaviours were influencing the variation in attributions and patterns of criticism between high and low EE relatives, then the attributions and pattern of criticism might be more similar between high EE and low EE relatives within the same households. They found that low EE relatives from high EE homes did attribute more behavioural control to patients than low EE relatives from low EE homes, which suggested that these relatives perceived the patient as more responsible for the illness. Weisman et al. (2000) proposed that there might be some form of 'contagion effect' in operation, whereby regular exposure to the high EE attitudes and attributions about the patient of high EE relatives influences the attitudes and attributions of low EE family members.

## **Gender of Relatives and Patients**

There has been some research, which has linked gender differences to causal attributions about schizophrenia. Weisman and López (1997) found that Anglo American males reported significantly higher controllable attributions for positive and negative symptoms and for the cause of the illness than females. However, no significant gender differences were found for Mexican participants. They hypothesised that nationality might moderate the relationship between gender and controllability attributions.

Weisman et al. (2000) found that the male relative was designated as high EE within high EE homes. They suggested that because of research evidence, which indicates that internal attributions might lead to high EE (e.g. Brewin et al. 1991; Barrowclough et al. 1994), male family members might be at greater risk than female family members for developing highly critical attitudes toward their mentally ill relatives. These findings appear to be consistent with other general research, which has suggested that men tend to make more internal attributions of control than women (Furnham 1984).

Finally, López et al.'s (1999) main finding was that patient's use of illicit drugs was positively related to family members' attributions of control and level of expressed emotion. However, they also found a trend in their data, which suggested that male patients were judged to have a worse clinical outcome than female patients. They hypothesised that men may be perceived as being more responsible for their behaviour than their female counterparts.

## **Knowledge About Schizophrenia**

Knowledge about schizophrenia has been used in some studies to predict EE. Brown et al. (1972) suggested that a lack of knowledge about schizophrenia was a major contributor to high EE and Barrowclough et al. (1987) found that less knowledge about the illness was associated with marked criticism. However, other studies failed to support these findings (e.g. Berkowitz et al. 1984). Harrison and Dadds (1992) and Harrison et al. (1998) have applied an attributional model of expressed emotion to caregivers of patients with a diagnosis of schizophrenia and have included a measure of knowledge about schizophrenia.

Both studies found very similar results regarding the relationship between carers' knowledge about schizophrenia and their causal attributions. They found that high EE relatives (criticism) had less knowledge about schizophrenia compared with high EOI or low EE relatives. They also found that knowledge was negatively correlated with internal attributions, meaning that the more knowledge relatives had about the illness the less likely they were to make internal attributions. They suggested that relatives' knowledge about schizophrenia appeared to be beneficial to the way that relatives related to the sufferer, where a higher level of knowledge reflected lower criticism and less likelihood of symptoms being attributed internally to the patient. They also reported that a lower level of knowledge was significantly negatively correlated with attributions of negative symptoms to personality of the sufferer rather than to the illness. They proposed that high EE relatives might be more critical of negative symptoms than low EE relatives because they are unaware that these behaviours reflect core symptoms of schizophrenia.

## **Cultural Factors**

A separate line of research has concerned cultural differences in controllability attributions and affect, in order to better understand why the course of schizophrenia is more favourable in 'developing' rather than 'developed' societies (World Health Organisation 1979). Jenkins et al. (1986) provided some observational evidence to support cross-cultural differences in attributions and affect towards individuals with a diagnosis of schizophrenia. Firstly, they suggested that Mexican-Americans, compared to Anglo-Americans, were more likely to perceive symptom-behaviour as part of a legitimate illness and therefore outside of the person's control. Secondly, that Mexican-Americans tended to express emotions of sadness, sorrow and concern, whereas Anglo Americans frequently expressed negative emotions, such as, anger and annoyance.

Weisman and López (1997) empirically tested Jenkins et al.'s (1986) observations. They found that Anglo Americans perceived the negative symptoms of schizophrenia to be significantly more controllable than their Mexican counterparts. However, they did not find any significant differences for controllable attributions for positive symptoms or the cause of the illness itself. Contrary to the hypothesis, they found that Anglo Americans, compared to Mexicans, reported greater positive affect towards positive symptoms but not negative symptoms and greater negative affect for both symptom types. They concluded that a 'blame free' view of schizophrenia, resulting in compassionate attitudes and prosocial, help-giving behaviours towards patients, might be a contributing factor to the more favourable clinical course of schizophrenia observed in developing countries.

Using data from the same participants, Weisman (2000) tested two hypotheses regarding the role of religion in shaping family members' attributions about schizophrenia. The first examined whether the ethnic differences in controllability attributions, could be explained by Mexicans' religious or spiritual tendencies to view negative events as rooted in divine factors beyond the patient's personal control. The second tested the hypothesis that more religious individuals may be more likely to perceive another persons adversity as a punishment for prior wrongdoings or for a failure to try to help oneself. Weisman (2000) found that greater religiosity was found to be significantly associated with increasing perceptions of behavioural controllability. This appears to be consistent with studies, which report that religion is sometimes used in a more dysfunctional way (see Weisman et al. 2000).

The results of all these studies highlight the fact that different patterns of attributions may reflect a range of different situational factors as well as differences in relatives' perceptions about the cause of schizophrenia.

Therefore, these findings stress the importance of including a range of situational factors when examining the relationship between relatives' causal attributions about schizophrenia and their subsequent coping responses.

## **CLINICAL INTERVENTION**

There have been two intervention-based studies, which have reported data on the affect of attributional change on relatives' behaviour. Medvene and Krauss (1989) recruited 57 group members of the National Alliance for the Mentally Ill (NAMI) self-help groups and studied the association between the quality of family relationships and attributions about the cause of the illness. Caregivers who attributed the illness to biological factors reported better relationships with

their relative than those who attributed the illness to psychogenic or moral factors. The results also indicated that improvements in the quality of the relationship were associated with shifts in attributions from psychogenic or moral factors to biological ones over time. They also found that current endorsement of the organic attribution was positively correlated with disclosure of the problem, whereas current endorsement of the psychogenic attribution was negatively associated with disclosure, suggesting that endorsement of attributions about organic causes was destigmatising. One of the methodological weaknesses of the study was its use of retrospective data, and therefore it needs replication. However, the authors speculated that the cognitive and behavioural changes found in this study might have been mediated by learning a comprehensive schema of information about schizophrenia that included information about causes, symptoms and methods of treatment. They also stated that self-help groups could constitute a potentially powerful social influence on people's causal attributions and their behaviours in coping with stress and the illness.

Brewin (1994) investigated whether changes in levels of criticism and hostility of 26 relatives' of patients with schizophrenia would be associated with their beliefs about the causes of the patients' symptoms and negative behaviours following intervention. The findings indicated that reductions in criticism were not related to attributional change. However, reductions in hostility were associated with significant shifts towards more universal and uncontrollable attributions, providing some evidence that EE and attributions may be functionally related. One of the weaknesses of both studies was that neither was designed as an attributional retraining programme. Brewin (1994) suggested that further research might involve fine-grained analysis of episodes leading to significant emotional change and by studies of attributional change during different types of intervention.



## **DISCUSSION**

### **Research Implications**

Many of the research groups concluded that future research should focus on developing a better understanding of the attributional beliefs held by relatives. They suggested that this would provide a more comprehensive view of how relatives cope with the potential difficulties of living with someone with a diagnosis of schizophrenia, which might result in more effective family interventions (e.g. Barrowclough et al. 1994; Medvene and Krauss 1989).

Harrison et al. (1998) suggested that future studies might benefit from applying attributional models to a much broader range of coping responses, for example, pity, guilt, ignoring, and emotional overinvolvement. López et al. (1999) and Robinson (1996) have also highlighted that many relatives cope well with the changes in behaviour and functioning that can accompany psychiatric impairment. Therefore, they have suggested that relatives' prosocial responses should be studied in order to determine successful coping strategies, which might be protective against relapse.

Other research groups have suggested that a valuable area of future research would be to gain a better understanding of family and patient factors that influence the development of causal attributions and consequent coping behaviour (e.g. Lieberman and Hinrichsen 1999). This includes the need for further research, which identifies and examines specific sociocultural factors that may underlie differences in relatives' attributions and emotional reactions towards individuals with a diagnosis of schizophrenia across cultures (Weisman and López 1997) and studies, which consider the profile of symptoms rather

than the tendency to focus on the effect of negative symptoms on caregivers (Harrison et al. 1998).

A number of studies have also highlighted the need for additional research into the health consequences of causal explanations that carers generate (e.g. Natale and Barron 1994; Barrowclough et al. 1996). Barrowclough et al. (1996) stressed the valuable role that cognitive processes might play in the development and maintenance of affective disorders of carers. They argued that it would be useful to apply cognitive models of coping and emotion in order to determine which caregivers are vulnerable to developing problems themselves, and to further clarify the different responses that family carers make towards their ill relative, including those categorised as high EE responses.

There are a number of methodological limitations and differences between many of the studies included in this review, which need consideration for future research (see Table 1). These include the small number of participants recruited in some studies, which limited the application of more sophisticated statistical analysis and also reduced the generalisability of the findings. A wide range of measurement tools have also been used to measure similar underlying constructs, such as controllability attributions, which might explain some of the variation in the results found. Finally, the use of cross-sectional and correlational designs makes it difficult to interpret the relationship between attributions and emotions and whether attributions mediate emotional change in relatives or whether they are a consequence of the relatives' emotions (e.g. Weisman et al. 1993; Robinson 1996). Therefore, longitudinal research is needed to examine this relationship over the course of the illness. Natale and Barron (1994) stressed the need to look at the relationship between causal attributions and depression in mothers of recently and not recently diagnosed sons.

Barrowclough et al. (1996) also stated that it is unclear whether relatives' self-blame is only significant at times of crisis when they might perceive their coping efforts to have failed or if this might be predictive of the relatives' continued distress following patient discharge.

### **Clinical Implications**

A number of studies have highlighted the importance of good clinical assessment of relatives' attributions. Bergen et al. (1997) suggested that it might be beneficial to use a LOC scale in an assessment battery to guide the clinical intervention. This was based on their findings that interventions might need to be individually adapted dependent on relatives' own LOC. They suggested that overinvolved relatives who score highly on a Chance LOC scale might benefit from an educational programme, which would enhance predictability in their lives. On the other hand, EOI relatives who score highly on a Powerful Others LOC scale might benefit from a more directive structured counselling approach, whereas a low Powerful Others LOC score might be indicative of a non-directive style, ensuring a feeling of autonomy. Weisman et al. (1993) and Weisman and López (1997) also suggested incorporating a measure of controllability and symptom type, in conjunction with EE measures, to contribute towards a more thorough assessment of the emotional climate within the home. They suggested that this might prove to be a useful tool for the prognosis of patients with a diagnosis of schizophrenia and for the identification of high-risk individuals.

Many of these empirical papers have concluded that clinical interventions designed to change carers' beliefs about the causes of schizophrenia and associated symptomatology might result in decreasing high EE (e.g. Brewin 1994). A number of studies have also highlighted the potential benefits of

educational components of psychosocial or family treatment packages. They have suggested that if families are taught that their relative has an illness it might make them less likely to employ social control strategies to deal with the difficulties they experience, thereby reducing levels of EE (e.g. Greenley 1986). However, it seems that different intervention strategies might be required for emotionally overinvolved relatives. These relatives may already hold strong medical beliefs about the patients' behaviour and educating them in order to develop illness attributions might reinforce their current attitudes, which might not be very successful (e.g. Harrison and Dadds 1992).

Robinson (1996) found that not blaming people for the illness was associated with positive family functioning and blaming people was associated with tendencies to be critical and overinvolved. Therefore, she suggested that one of the most important and successful aspects of psychoeducation might involve reframing cognitions and promoting attributions that do not blame people for the illness. Medvene and Krauss (1989) also suggested that interventions based on reducing parental self-blame might reduce their guilt and motivation to engage in overprotective behaviours. They also proposed that reducing parental blaming of the patient might reduce their anger towards the person and their motivation to engage in hostile or critical behaviours. There are also implications for service providers. Barrowclough et al. (1996) stated that service providers who contribute towards carers feeling of self-blame should be aware that they might be responsible for increasing the person's level of psychological distress.

Finally, a number of papers have highlighted the need to include information that negative symptoms are integral components of schizophrenia and to stress the uncontrollability of these alongside positive symptoms (e.g. Harrison et al. 1998; Weisman et al. 1998, Weisman and López 1997; Weisman et al. 2000). It is

thought that this might decrease blameworthy attributions for negative symptoms. However, Provencher and Mueser (1997) pointed out that relatives who believed that patients with schizophrenia had no responsibility for their negative symptom behaviours experienced increased levels of objective burden. They concluded that clinicians might need to help relatives to understand that although negative symptoms might be a characteristic of schizophrenia, change was still possible. López et al. (1999) suggested that it might be helpful for relatives to adopt a flexible attributional stance about whether their relative has control over their behaviour. This would need to be assessed at an individual level and would depend on the context; for example, patients might have control over some behaviour, such as illicit drug use, but not over others, such as attention difficulties. They suggested that future research could help to determine whether a flexible attributional stance, one which could be adjusted over time and across situations, would be useful in addressing the ongoing challenges that families face in living with relatives with a diagnosis of schizophrenia.

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## **Chapter Two**

### **Brief Research Paper**

**The Development of the Attributions for Schizophrenia  
Questionnaire (ASchizQ): A Preliminary Investigation in  
Staff Carers of Individuals with an Intellectual Disability  
and Schizophrenia.**

**Prepared for submission to the  
Journal of Applied Research in Intellectual Disabilities**

## **Abstract**

**Background.** There has been a growing interest in the application of attribution theory and the measurement of causal attributions in the intellectual disability and schizophrenia literature. Despite this, research has neglected to explore the causal attributions of staff caring for individuals with a dual diagnosis of a mild intellectual disability and a diagnosis of schizophrenia. Therefore, an instrument to measure the causal attributions of this group of carers has also not been developed.

**Method.** The present study describes the development of the Attributions for Schizophrenia Questionnaire (ASchizQ) and reports preliminary psychometric data of administering it with 46 community staff carers of 9 individuals with a dual diagnosis.

**Results and Conclusions.** The results indicated that the ASchizQ has acceptable levels of reliability and can be applied as a satisfactory measure of causal attributions of schizophrenia. The research and clinical implications are discussed.

## Introduction

During the past decade the application of attribution theory and the measurement of carers' causal attributions has received increased interest in both the intellectual disability and schizophrenia literature. Researchers in intellectual disabilities have begun to apply Weiner's (1980, 1986) attribution theory of helping behaviour to develop current understanding about staff carers' cognitive, emotional and behavioural responses towards adults who have an intellectual disability and challenging behaviour (e.g. Dagnan *et al.* 1998; Standen & Stanley 2000). This work has evolved from researchers working within the behavioural paradigm who have demonstrated that staffs' beliefs about the causes of challenging behaviour can influence their commitment or lack of commitment to implement care programmes, which are known to fail (see Allen 1999 and Hastings 1997a for reviews).

In schizophrenia research, studies have investigated how relatives' attributions about the cause of schizophrenia and associated symptomatology might help to explain different coping responses towards their relatives' illness (see Chapter One). This research has predominantly focused on the concept of expressed emotion, particularly relatives' criticism, hostility and emotional overinvolvement (high EE). This is because there is a significant body of literature, which indicates that the course and outcome of schizophrenia is highly responsive to the psychosocial environment and emotional atmosphere within the family (see Wearden *et al.* 2000 for a review).

Despite this research, attribution theory has not yet been applied to staff caring for those with a dual diagnosis of schizophrenia and a mild intellectual disability. Therefore, an instrument to measure the causal attributions of this group of

carers has also not been developed. The present paper will highlight existing methods of attributional measurement in these two fields, in order to inform the development of a new tool, the Attributions for Schizophrenia Questionnaire (ASchizQ). It will then report some preliminary psychometric data of administering this instrument to staff carers of individuals with a dual diagnosis.

There have been a variety of methodologies used to assess staff carers' causal attributions about the challenging behaviour of individuals with intellectual disabilities. These have included, direct interviews with staff (Hastings 1995), written responses to open-ended questions (Berryman *et al.* 1994), modified versions of the attributional style questionnaire (Peterson *et al.* 1982) (e.g. Cottle *et al.* 1995; Dagnan *et al.* 1998; Standen & Stanley 2000) and self-completion ratings scales, such as the Self-Injury Behavioural Understanding Questionnaire (SIBUQ; Oliver *et al.* 1996) and the Challenging Behaviour Attributions Questionnaire (CHABA; Hastings 1997b). One of the limitations of some of these methods is that they are based on carers' responses to theoretical rather than real-life events (e.g. Berryman *et al.* 1994; Dagnan *et al.* 1998). Therefore, research is needed which links carers' cognitions, emotions and behaviours in clinical practice (see Allen 1999). Also, none of these instruments have been specifically designed to measure staff carers' attributions about the cause of schizophrenia in individuals with a dual diagnosis.

In schizophrenia research, a wide range of methodologies has been developed to assess relatives' attributions about schizophrenia and the associated symptomatology. The Camberwell Family Interview (CFI; Vaughn & Leff 1976b) is one of the main methods and has been used to elicit relatives' spontaneous casual attributions (e.g. Brewin *et al.* 1991; Barrowclough *et al.* 1994; Weisman

*et al.* 1993). However, this requires a considerable time commitment to transcribe, extract and code the attributional statements.

A number of other tools have also been developed or adapted to allow for direct scoring of causal attributions, including those that enable the assessment of relatives' attributions about the positive and negative symptoms of schizophrenia. This separate consideration for positive and negative symptoms has been based on Hooley's (1987) illness attribution and controllability model. This proposed that positive symptoms (e.g. hallucinations and delusions) were more likely to be attributed to the patients' illness and therefore perceived as uncontrollable by the patient. However, negative symptoms (e.g. apathy and social withdrawal) were more likely to be attributed to the patients' personality characteristics and therefore perceived as controllable by the patient. Examples of these instruments include, the Attribution of Symptoms Inventory (Harrison & Dadds 1992), the Attribution Scale for Symptom Behaviours (Provencher & Mueser 1997), and the Causal Dimension Scale (Russell 1982) adapted by Weisman and López (1997). However, none of these tools enable carers to identify their own causal attributions and rate them on a full range of the underlying attributional dimensions (see Munton *et al.* 1999).

Based on this research, several considerations led to the format employed for the Attributions for Schizophrenia Questionnaire (ASchizQ). The first was to measure the degree to which staff carers working with individuals with a dual diagnosis used a wide range of attributional dimensions. The second was to ask them to respond to recent real-life events rather than theoretical vignettes. The third was to enable them to identify their own causes about the symptoms associated with a diagnosis of schizophrenia, including positive and negative symptoms, and rate them on underlying attributional dimensions. This would

allow for simple and objective quantification of responses and reduce researcher bias in interpreting attributional dimensions (Peterson *et al.* 1982).

## **Method**

### **Procedure**

The participants were recruited as part of a larger study (see Chapter Three). Participants were community staff carers of individuals (clients) with a dual diagnosis of a mild intellectual disability and schizophrenia. The individuals that staff were caring for were required to have a diagnosis of schizophrenia as assessed by their Consultant Psychiatrist using the ICD-10 diagnostic criteria, to have a premorbid intellectual disability prior to the onset of schizophrenia and to be aged between 18-65 years. Consultant Psychiatrists in Warwickshire recruited the participants by sending information booklets (see Appendix E & F) and a covering letter (see Appendix G) explaining the purpose of the study, to 21 clients and their staff carers who met the inclusion criteria. They expressed their interest in taking part in the research by returning a tear-off slip to their Consultant Psychiatrist. At this point an appointment was made for the researcher to meet with the client and a staff carer who knew them well to explain the nature of the research further.

In accordance with the DCP Professional Practice Guidelines (1995) a process of informed consent was carried out for each individual with a dual diagnosis and then for each staff carer. Two information booklets (see Appendix E & F) were developed for the research, one for the staff carers and one for use with the individuals with intellectual disabilities. The latter was used flexibly with each individual in conjunction with the Protocol and Record of Assessment of Client's

Capacity to Make a Decision (Brooklands Multidisciplinary Consent Working Party, North Warwickshire NHS Trust, 1998/2000) (see Appendix H) and with research which highlights methods for addressing and gaining consent to psychological research by people with an intellectual disability (e.g. Arscott *et al.* 1998; Freedman 2001). If consent was gained (see Appendix I & J for consent forms) the researcher explained the questionnaires and went through the ASchizQ (see Appendix K) with each staff carer.

### **Participants**

The participants were 46 community staff carers of 9 individuals with an intellectual disability and an ICD-10 diagnosis of schizophrenia, which represented an overall response rate of 43%. 84% of the staff carers who agreed to participate returned their questionnaires. The staff carers had a mean age of 40.4 years (SD = 11.4), nine were male (19.6%) and 37 were female (80.4%). They all worked in community-based residential homes, which included group homes and individual tenancies. The number of other service users in each community setting ranged from 0 to 15 (mean = 4.9, S.D. = 6). Staff carers had worked with individuals with intellectual disabilities between 6 months and over 7 years (mode = over 7 years, 39.1%). Ten (21.7%) of the staff had professional nursing qualifications or were in managerial positions. The remaining 36 (78.3%) were support workers. 25 staff (54.3%) reported receiving some support or training related to schizophrenia or mental health difficulties.

The individuals with a dual diagnosis had a mean age of 37.8 years (SD = 8), 3 were female (33.3%) and 6 were male (66.6%). Staff carers had also worked with these individuals between 6 months and over 7 years (mode = 6-12

months, 21.7%) and spent between 9 and 49 hours working with them in an average week (mode = 9 hours, 32.6%).

## **Measures**

### **The Development of the Attributions for Schizophrenia Questionnaire (ASchizQ) (see Appendix K)**

The Attributions for Schizophrenia Questionnaire (ASchizQ) is a modified form of the Attributional Style Questionnaire (Peterson *et al.* 1982) and includes seven attributional dimensions. The four additional attributional dimensions included in this questionnaire were developed by Cottle *et al.* (1995) to measure staff causal attributions about violent incidents of individuals with an intellectual disability and additional mental health or behavioural difficulties.

The ASchizQ includes five brief descriptions and examples of the main characteristic symptoms of schizophrenia identified in the DSM-IV (1994). These are delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour and negative symptoms. A range of resources were used to develop these items, for example, diagnostic tools and manuals (e.g. DC-LD 2001; DSM-IV 1994; PAS-ADD 1993) and current literature (e.g. Doody *et al.* 1998; James & Mukherjee 1996; Meadows *et al.* 1991; Turner 1989), and were worded in such a way as to enable a range of staff carers to understand them.

Staff carers were asked to read each of the five descriptions in relation to the person they cared for. They were asked to rate how frequently the person had these experiences in the past month on a 5-point likert scale, which ranged from not present (0) to all of the time (5). They then wrote down one main cause of



the experience and rated their attributions for the cause on 7-point bipolar scales (1-7) for each of the seven attributional dimensions. These dimensions included internal-external, controllable-uncontrollable, personal-universal, global-specific and stable-unstable for staff carers' perception of the individuals' causal role in events. In addition, separate attributional ratings for internal-external and controllable-uncontrollable were made for staff carers' perception of their own causal role in events. Higher scores on these dimensions indicated greater internality, uncontrollability, universality, globality and stability.

## **Results**

### **Attributions for Symptoms of Schizophrenia**

A mean score for each of the seven attributional dimensions was obtained for each staff carer. These were calculated by dividing staff carers total score on a particular attributional dimension by the number of rateable attributions contributing to the total score (see Table 1). The results indicate that staff carers' attributions for the clients' causality were internal (mode = 5), uncontrollable (mode = 6), personal (mode = 2), global (mode = 6) and stable (mode = 7). Attributions for staff carers' causality were external (mode = 1) and uncontrollable (mode = 4).

Mean scores were also calculated for each attributional dimension for positive symptoms (delusions, hallucinations, disorganised speech and grossly disorganised or catatonic behaviour) and negative symptoms (see Table 1). The distinction between positive and negative symptoms was based on the DSM-IV criteria (1994). A paired *t* test was carried out to test for differences between the attributional dimensions for these two schizophrenia symptom groups (see Table

1). In this paper, a 1% level of significance was set in order to reduce the number of type one errors. No significant differences were found between the two schizophrenia symptoms groups.

**Table 1** Mean and standard deviations for each attributional dimension on the ASchizQ for all symptoms and for positive and negative symptoms.

	All Symptoms <i>n</i> = 46 M (SD)	Positive Symptoms (Delusions, Hallucinations, Disorganised Speech, Grossly Disorganised or Catatonic Behaviour) <i>n</i> = 45 M (SD)	Negative Symptoms <i>n</i> = 38 M (SD)	<i>t</i> value (2-tailed sig.) <i>n</i> = 37
Internal (client)	4.64 (1.38)	4.49 (1.36)	4.94 (1.90)	1.46 (0.15)
Controllable (client)	4.61 (1.25)	4.58 (1.54)	4.74 (1.90)	0.95 (0.35)
Personal (client)	3.77 (1.60)	3.71 (1.69)	4.13 (2.00)	2.02 (0.05)
Global (client)	5.52 (1.10)	5.49 (1.23)	5.37 (1.42)	-0.14 (0.88)
Stable (client)	5.89 (1.28)	5.85 (1.27)	6.03 (1.35)	0.29 (0.77)
Internal (staff carer)	2.19 (0.88)	2.21 (0.94)	2.21 (1.19)	-0.24 (0.81)
Controllable (staff carer)	4.50 (1.53)	4.32 (1.64)	5.08 (1.78)	2.66 (0.03)

### Internal Reliability of the ASchizQ

The internal reliability of each attributional dimension was estimated using Cronbach's coefficient alpha (see Table 2). The results indicated that the personal, global and stable attributional dimensions for clients' causality and the internal and controllable attributional dimensions for staff carers' causality had acceptable to good levels of internal reliability. The internal and controllable attributions dimensions for clients' causality were the least reliable dimensions, 0.50 and 0.54 respectively.

**Table 2** Cronbach's coefficient alphas for the ASchizQ attributional dimensions.

ASchizQ Attributional Dimensions	Cronbach's coefficient alpha
Internal – External (Client)	0.50
Controllable – Uncontrollable (Client)	0.54
Personal – Universal (Client)	0.81
Global – Specific (Client)	0.76
Stable – Unstable (Client)	0.88
Internal – External (Carer)	0.77
Controllable – Uncontrollable (Carer)	0.82

Pearson correlation coefficients were then computed between the mean attributional dimensions for all symptoms and are shown in Table 3. There was a significant negative correlation between personal and internal attributions, meaning that making attributions that were more personal to the client was significantly correlated with attributions that were also more internal to the client. However, this was not so highly correlated to suggest that the scales did not have sufficient unique variance.

**Table 3** Correlations between the mean attributional dimensions for all symptoms measured by the ASchizQ.

	Internal (client)	Controllable (client)	Personal (client)	Global (client)	Stable (client)	Internal (staff carer)	Controllable (staff carer)
Internal (client)							
Controllable (client)	0.96 (0.53)						
Personal (client)	-0.39** (0.01)	0.36* (0.02)					
Global (client)	0.19 (0.20)	0.17 (0.25)	0.17 (0.27)				
Stable (client)	0.01 (0.93)	0.20 (0.17)	0.05 (0.76)	-0.08 (0.62)			
Internal (staff carer)	-0.12 (0.42)	0.09 (0.54)	0.02 (0.92)	-0.07 (0.63)	0.32* (0.03)		
Controllable (staff carer)	0.24 (0.10)	0.26 (0.08)	0.02 (0.90)	0.11 (0.45)	0.30* (0.05)	-0.09 (0.54)	

\*Correlation significant at the 0.05 level (two-tailed) \*\*Correlation significant at the 0.01 level (two-tailed)

## Discussion

This paper has reported some of the preliminary psychometric properties of the Attributions for Schizophrenia Questionnaire (ASchizQ). This preliminary data suggests that the ASchizQ has acceptable levels of reliability and can be applied as a satisfactory measure of causal attributions. Therefore, this enables the application of attribution theory to staff carers' working with individuals with a dual diagnosis.

The internal consistencies for the attributional dimensions were generally moderate to good in size, which indicated that the sub-scales are reliable and composed of homogenous item sets. However, the internal and controllable

attributional dimensions for clients' causality were the least consistent. Barker *et al.* (1994) indicate that these are acceptable for pilot investigations. Also these findings are similar to those found for the Attributional Style Questionnaire (Peterson *et al.* 1982) and the Expanded Attributional Style Questionnaire (Peterson & Villanova 1988), which are widely used assessment tools of attributional style. In these papers, the internality dimension was reported as the least reliable dimension, 0.46 and 0.66 respectively. In future research, the internal reliability of the ASchizQ might be improved by increasing the number of items, which comprise each attributional dimension.

The preliminary correlational analyses suggest that the attributional dimensions are independent of each other. However, future research would benefit from further investigation of the internal structure of the questionnaire, factor analysis. The ASchizQ can be applied to any population of individuals with a diagnosis of schizophrenia, for example, carers of individuals with a diagnosis of schizophrenia but without an intellectual disability. A further study using this population might be able to recruit a significantly larger number of participants than the current study. This would be required for factor analysis in order to produce clear factor structures (see Kline 1994).

Further research is also warranted on other properties of the scale, for example, the stability of the test re-test reliability and its validity. Concurrent validity of staff carers' causal attributions is difficult to establish given the lack of external validation criteria, none of the current attribution questionnaires for schizophrenia measure the full range of attributional dimensions. However, it may be possible to use the ASchizQ to monitor the causal attributions of staff carers who receive a psychosocial training package, where one would expect

that there might be some change in staff carers causal attributions about schizophrenia and associated symptomatology over time.

Further research on the clinical utility and practical value of the ASchizQ is also warranted. This might usefully involve replicating this research within other contexts, for example, with family carers, day services and inpatient staff carers. Another useful clinical application might be to include the ASchizQ as part of an assessment battery in order to better understand cognitive factors which influence staff carers motivation and performance (see Kushlick *et al.* 1997). This would then serve to inform clinical interventions and training initiatives for this group of carers.

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## **Chapter Three**

### **Main Research Paper**

# **Carers' Attributions for Learning Disabilities and Schizophrenia**

**Prepared for submission to the  
British Journal of Clinical Psychology**

## **Abstract**

**Objectives.** The main purpose of this study was to draw on Weiner's attributional model of helping behaviour and relevant research findings to examine the relationship between causal attributions about schizophrenia and the coping responses of staff caring for individuals with a mild learning disability and a diagnosis of schizophrenia.

**Design and method.** The participants were 46 community staff carers who worked with 9 individuals with a mild learning disability and a diagnosis of schizophrenia. Staff carers completed the Attributions for Schizophrenia Questionnaire (ASchizQ) and the Carer Coping Style Questionnaire (CCSQ). Correlational analysis was employed to examine the relationships between the causal attributions and coping styles of these staff carers.

**Results and Conclusions.** The hypotheses were not supported. However, external, uncontrollable attributions to the staff carers' perception of their own causal role in events were significantly correlated with emotionally overinvolved and resigned coping styles. The clinical and research implications of the findings are discussed in relation to the experience of caring for individuals with a mild learning disability and a diagnosis of schizophrenia.

## **Introduction**

Several epidemiological studies have demonstrated that the prevalence of psychiatric disorders among people with learning disabilities is significantly higher than in the general population (Corbett, 1979; Heaton-Ward, 1977; Lund, 1985) and that people with learning disabilities are probably at greater risk of developing mental health problems (Borthwick-Duffy & Eyman, 1990). Turner (1989) estimated that the prevalence rate for schizophrenia in people with learning disabilities was about 3%, which is three times higher than the general population. Despite these findings, research in this field has been fairly limited. Studies have primarily concentrated on epidemiology (e.g. Turner, 1989), assessment and diagnosis (e.g. Moss, Prosser & Goldberg, 1996; Singh, Sood, Sonenklar & Ellis, 1991; Sturmey, Reed & Corbett, 1991), description of clinical phenomena (e.g. James, Mukherjee & Smith, 1996; Meadows, Turner, Cambell, Lewis, Revelley & Murray, 1991; Reid, 1972;), and links with other genetic and medical factors (e.g. Doody, Johnstone, Sanderson, Cunningham-Owens & Muir, 1998; O'Dwyer, 1997).

Psychological research involving these individuals and their carers has been neglected. One of the possible reasons for this might be related to the fact that until recently a large number of people with learning disabilities have lived in segregated hospitals and as they have moved into smaller community homes their psychological and mental health needs have become more visible (Prosser, 1999). Community carers tend to be support staff that receive little or no education or training about the mental health needs of this group of individuals and have been reported to have a low level of knowledge about psychotic symptoms (Quigley, Murray, McKenzie & Elliott, 2001). Therefore, they may well have difficulties recognising the signs and symptoms of

schizophrenia, understanding their significance and obtaining appropriate support for the person they care for and for themselves (see Prosser, 1999). It is argued that research examining the experience of staff caring for individuals with a mild learning disability and a diagnosis of schizophrenia, including the relationship between attributions about the cause of schizophrenia and their coping responses, has been overlooked. Evidence from schizophrenia and learning disabilities research, which has investigated carers' causal attributions, would suggest that this is a significant omission. These studies will be highlighted below to inform the development of the current study.

In schizophrenia research, attributional models have been used to investigate how relatives' attributions about the cause of schizophrenia and associated symptomatology might help to explain different coping responses towards their relatives' illness (see Chapter One for a review). This research has largely focused on relatives' expressed emotion (EE) (criticism, hostility, emotional overinvolvement and warmth) due to the significant body of literature, which has indicated that the course and outcome of schizophrenia is highly responsive to the psychosocial environment and emotional atmosphere within the family unit (see Kavanagh, 1992; Bebbington & Kuipers, 1994; Wearden, Tarrier, Barrowclough, Zastowny & Armstrong-Rahill, 2000 for reviews).

One influential attribution theory has been Weiner's (1980, 1986) model of helping behaviour. This model suggests that different causal beliefs about other people's problems will be instrumental in producing specific emotional states, which in turn play a role in motivated behaviour. Weiner (1980, 1986) demonstrated experimentally that internal, controllable attributions (e.g. lack of effort or drunkenness) led to negative affects such as anger and disgust and resulted in negative behavioural responses, for example, avoidance, neglect and

judgements about not giving help. Brewin (1988) suggested that EE researchers might conceptualise this as a critical and/or hostile response. However, external, uncontrollable attributions (e.g. an individual's ability level or restricted opportunities) generated positive affects such as sympathy and pity and led to positive behavioural responses, such as approach behaviour, support and judgements about help giving. EE researchers might conceptualise this as low EE (warmth). Relatives designated as low EE (warmth) have been found to respond to the symptoms associated with a diagnosis of schizophrenia with greater patience, understanding and a tolerant non-intrusive approach to coping. This has been thought to contribute to less stress and a more favourable outcome (Hooley, 1987).

Weiner's (1980, 1986) attribution theory has also been used to understand relatives' emotional overinvolvement (e.g. Brewin, MacCarthy, Duda & Vaughn, 1991; Vaughn & Leff, 1976a). It has been suggested that the underlying emotional experiences of these individuals might be guilt and protectiveness. Weiner (1986) proposed that guilt is generally experienced when individuals attribute the cause of a negative event as internal and controllable to themselves, whereas protectiveness might be related to experiencing pity.

Barrowclough, Johnston and Tarrrier (1994) proposed that different attributional dimensions might mediate the different coping responses of high EE relatives. For example, internal, controllable attributions might result in efforts to persuade or coerce the patient to improve or restore his/her behaviour back to pre-illness levels or to behave normally (a critical/hostile attitude). This type of coping might be stressful for a vulnerable person with a diagnosis of schizophrenia and may consequently lead to relapse. On the other hand, external, uncontrollable attributions might result in relatives attempting to improve events by using



themselves as a buffer between the patient and the outside world by taking control and doing things for them (self-sacrificing and intrusive behaviours). These coping responses might not represent increased stress but may serve to maintain symptoms in the longer term.

During the last 20 years, a number of empirical studies have provided evidence, which indicates that relatives' coping responses might be mediated by their causal attributions about schizophrenia and associated symptomatology (see Chapter One). Brewin et al. (1991) found that hostile relatives made internal, personal and controllable attributions and critical relatives made attributions that were more personal and controllable by the patient. The attributions of emotionally overinvolved (EOI) relatives were not different from low EE relatives, who made the most external and universal attributions about the patients' behaviour. Barrowclough et al.'s (1994) results were slightly different. They found that critical relatives made more internal attributions to the patient, whereas hostile relatives tended to make attributions that were controllable and personal to the sufferer. Using a different methodology, Weisman, López, Karno and Jenkins (1993) also found that critical families made more controllable attributions than low EE families. Their results also indicated a relationship between controllable attributions and the expression of more negative affect towards the patient, such as anger and annoyance.

A number of studies have also examined the influence of different situational factors on the patterns of attributions made by the relatives of patients with schizophrenia (see Chapter One). Among these factors are the age of the client, the relatives' gender and their knowledge about schizophrenia. Greater age has been related to making more controllable and internal attributions (Brewin et al., 1991; Butler, Brewin & Forsythe, 1986). Weisman and López (1997) found that

male relatives of patients with a diagnosis of schizophrenia reported significantly higher controllable attributions than female relatives. This appears to be consistent with other general research, which suggests that men tend to make more internal attributions of control than women (Furnham, 1984). Finally, Harrison and Dadds (1992) and Harrison, Dadds and Smith (1998) have reported that carers' knowledge about schizophrenia is negatively related to their internal attributions, meaning that the more knowledge carers have about the illness the less likely they are to make internal attributions.

The research highlighted so far relates to relative carers of patients with a diagnosis of schizophrenia. However, this study concerns the relationship between staff carers' attributions about the cause of schizophrenia in individuals with mild learning disabilities and their coping responses, which has been neglected in the research literature. Therefore, the current study will also be informed by research findings, which highlight this relationship in staff carers working in psychiatric and learning disability services. These papers will be highlighted below.

The relationship between psychiatric care staffs' causal attributions and their coping responses has received very little attention. Sharrock, Day, Qazi and Brewin (1990) drew on Weiner's (1980, 1986) attribution theory of helping behaviour to study professional staffs' causal attributions about the behaviour of a patient with a personality disorder and a borderline learning disability on a medium secure unit. They found that stable and controllable attributions were negatively correlated with optimism, which was the best predictor of staffs' willingness to offer extra help. Barrowclough, Haddock, Lowens, Connor, Pidliswyi and Tracey (2001) studied key workers causal attributions about the behaviour of clients with a severe mental illness and a history of difficult to

manage behaviour on a closed inpatient facility. The findings indicated that critical comments were associated with making more stable attributions. However, there were no other associations between attributions and the EE dimensions. They did find that staff tended to view the behaviours of patients they felt less positively disposed towards as more controllable, which is consistent with attribution research for relative carers.

In learning disability settings, staff beliefs have been found to be a significant factor in determining their response to individuals who have a learning disability and challenging behaviour (see Allen, 1999; Hastings, 1997 for reviews). However, there are only a handful of studies, which have applied Weiner's (1980, 1986) attribution theory to develop the understanding of staff carers' cognitive, emotional and behavioural responses to individuals who challenge services. Cottle, Kuipers, Murphy and Oakes (1995) found that high EE compared to low EE staff tended to make more internal and personal attributions about the client and less controllable attributions for their own causal role, following a violent incident. Dagnan, Trower and Smith (1998) replicated Sharrock et al.'s (1990) study and found that staff carers' helping behaviour was also best predicted by optimism, which was in turn best predicted by negative emotion and controllable attributions. However, Stanley and Standen (2000) found that positive affect, rather than optimism, best predicted staff carers' helping behaviour. They found that challenging behaviours, which were perceived as more externally directed and more independent, led to greater attributions of carer control, negative affect and less propensity to help. However, challenging behaviours, which were perceived as being more self-directed and dependent, led to greater attributions of stability, positive affect and propensity to help.

It is difficult to draw too many conclusions, due to the small number of studies reporting on the relationships between staff carers' causal attributions and their coping responses. However, there is evidence, which indicates that attributional processes are important in staff-patient relationships (Barrowclough et al., 2001) and that carers' causal attributions are related to different types of coping responses across different client groups and different settings.

The context of the study to be reported is community staff carers supporting individuals with a mild learning disability and a diagnosis of schizophrenia. Given the limited previous work in this area, the aims of this study were, first, to relate situational factors such as the age of the client, the gender of the staff carer and their training and knowledge about schizophrenia to the pattern of causal attributions made by staff carers. Second, to explore the relationship between a broad range of staff carers' causal attributions about schizophrenia with a wide range of coping styles. Third to draw on Weiner's (1980, 1986) attribution theory of helping behaviour and research findings to test out a number of hypotheses. First, to test the hypotheses that internal, controllable attributions to the client would be significantly positively correlated with unhelpful coping styles, such as criticism/coercion, collusion, passivity or resignation. Second, to test the hypothesis that external, uncontrollable attributions to the client would be significantly positively correlated with helpful coping styles, such as warmth, constructiveness and reassurance and also with unhelpful coping styles, such as emotional overinvolvement and overprotectiveness. Finally, to test the hypothesis that internal, controllable attributions to the staff carers themselves would be significantly positively correlated with emotionally overinvolved and overprotective coping styles.

## **Method**

### ***Procedure***

Participants were community staff carers of individuals (clients) with a dual diagnosis of a mild learning disability and schizophrenia. The individuals that staff were caring for were required to have a diagnosis of schizophrenia as assessed by their Consultant Psychiatrist using the ICD-10 diagnostic criteria, to have a premorbid learning disability prior to the onset of schizophrenia and to be aged between 18-65 years. Consultant Psychiatrists in Warwickshire recruited the participants by sending information booklets (see Appendix E & F) and a covering letter (see Appendix G) explaining the purpose of the study, to 21 clients and their staff carers who met the inclusion criteria. They expressed their interest in taking part in the research by returning a tear-off slip to their Consultant Psychiatrist. At this point an appointment was made for the researcher to meet with the client and a staff carer who knew them well to explain the nature of the research further.

In accordance with the DCP Professional Practice Guidelines (1995) a process of informed consent was carried out for each individual with a dual diagnosis and then for each staff carer. Two information booklets (see Appendix E & F) were developed for the research, one for the staff carers and one for use with the individuals with learning disabilities. The latter was used flexibly with each individual in conjunction with the Protocol and Record of Assessment of Client's Capacity to Make a Decision (Brooklands Multidisciplinary Consent Working Party, North Warwickshire NHS Trust, 1998/2000) (see Appendix H) and with research which highlights methods for addressing and gaining consent to psychological research by people with a learning disability (e.g. Arscott et al.

1998; Freedman 2001). If consent was gained (see Appendix I & J for consent forms) the researcher explained the questionnaires and went through the ASchizQ (see Appendix K) with each staff carer.

### ***Participants***

The participants were 46 community staff carers of 9 individuals with a learning disability and an ICD-10 diagnosis of schizophrenia, which represented an overall response rate of 43%. 84% of the staff carers who agreed to participate returned their questionnaires. The staff carers had a mean age of 40.4 years (SD = 11.4), nine were male (19.6%) and 37 were female (80.4%). They all worked in community-based residential homes, which included group homes and individual tenancies. The number of other service users in each community setting ranged from 0 to 15 (mean = 4.9, S.D. = 6). Staff carers had worked with individuals with learning disabilities between 6 months and over 7 years (mode = over 7 years, 39.1%). Ten (21.7%) of the staff had professional nursing qualifications or were in managerial positions. The remaining 36 (78.3%) were support workers. 25 staff (54.3%) reported receiving some support or training related to schizophrenia or mental health difficulties. This included attendance at mental health training days, support from colleagues and from a specialist psychosis service for people with learning disabilities, and professional and personal experience.

The individuals with a dual diagnosis had a mean age of 37.8 years (SD = 8), 3 were female (33.3%) and 6 were male (66.6%). Staff carers had also worked with these individuals between 6 months and over 7 years (mode = 6-12 months, 21.7%) and spent between 9 and 49 hours working with them in an average week (mode = 9 hours, 32.6%).

## **Measures**

### **Demographic Questionnaires** (see Appendix L & M).

All staff carers were asked to complete a demographic questionnaire. One key staff carer was also asked to complete a demographic questionnaire for the individual with the dual diagnosis.

### **Knowledge about Schizophrenia** (see Appendix N).

The Knowledge Questionnaire (Smith & Birchwood, 1987) was used to assess staff carers' knowledge and understanding about schizophrenia. It is a 23-item multiple-choice questionnaire incorporating six subscales (demography, aetiology, symptoms, treatment, hospital procedures and coping). It is described as being quick and easy to complete, can be rated reliably and has face-validity for the carer.

### **Causal Attributions** (see Appendix K).

The Attributions for Schizophrenia Questionnaire (ASchizQ) was designed by the author to measure staff carers' attributions about the symptoms associated with a diagnosis of schizophrenia (see Chapter Two). The ASchizQ is a modified form of the Attributional Style Questionnaire (Peterson et al. 1982), which includes seven attributional dimensions. The ASchizQ includes five brief descriptions and examples of the main characteristic symptoms of schizophrenia identified in the DSM-IV (1994). These are delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour and negative symptoms.

Staff carers were asked to read each of the five descriptions in relation to the person they cared for. They were asked to rate how frequently the person had

these experiences in the past month on a 5-point Likert scale, which ranged from not present (0) to all of the time (5). They then wrote down one main cause of the experience and rated their attributions for the cause on 7-point bipolar scales (1-7) for each of the seven attributional dimensions. These dimensions included internal-external, controllable-uncontrollable, personal-universal, global-specific and stable-unstable for staff carers' perception of the individuals' causal role in events. In addition, separate attributional ratings for internal-external and controllable-uncontrollable were made for staff carers' perception of their own causal role in events. Higher scores on these dimensions indicated greater internality, uncontrollability, universality, globality and stability.

The internal reliability of each attributional dimension was estimated using Cronbach's coefficient alpha, which indicated that the personal, global and stable attributional dimensions for clients' causality and the internal and controllable attributional dimensions for staff carers' causality had acceptable to good levels of internal reliability (alpha 0.76-0.88). The internal and controllable attributional dimensions for clients' causality were the least reliable dimensions, 0.50 and 0.54 respectively.

***Coping Styles*** (see Appendix O).

The Carer Coping Style Questionnaire (CCSQ; Budd, Oles & Hughes, 1998) is a self-report questionnaire measure of carer coping style and was developed to mirror comments that are typically made by carers of people who have a diagnosis of schizophrenia in order to enhance face validity. It was designed to assess the four dimensions of expressed emotion (Leff & Vaughn, 1985) and the seven coping styles identified by Birchwood and Cochrane (1990). The CCSQ is a 91-item questionnaire measuring nine coping styles: emotional overinvolvement, collusion, criticism/coercion, passive, resignation and



overprotectiveness (unhelpful coping styles), and constructive, reassurance and warmth (helpful coping styles). Each item is scored on a 5-point Likert scale, where 5 represents the highest score. An initial analysis of the CCSQ indicated that eight of these coping styles had alpha-coefficients greater than 0.7, and six had alpha coefficients greater than 0.8, demonstrating that the sub-scales were reliable and composed of homogenous item sets.

Twelve members of a Community Learning Disability Team gave feedback on each item of the questionnaire and consequently it was modified for use in this population. The adaptations were limited to those necessary to make the questionnaire appropriate for carers of people with a dual diagnosis (see Appendix P for modifications). The internal reliability of these modified sub-scales was estimated using Cronbach's coefficient alpha. The results indicated that eight of the nine subscales had acceptable to good levels of internal reliability (alpha 0.68 – 0.80). The internal reliability of the overprotectiveness subscale was not found to be acceptable (alpha 0.31).

## **Results**

The means and standard deviations for each of the measures are presented in Table 1. The 23 items on the Knowledge Questionnaire were summated to obtain a total knowledge score for each staff carer. The mean knowledge score for these staff carers was 41% (9.35). This questionnaire has not been used with carers in learning disability settings. Therefore, the only means of comparison is with family carers in non-learning disabled populations. Smith and Birchwood (1987) described an educational intervention for two groups of family carers of patients with a diagnosis of schizophrenia, whose mean pre-intervention

knowledge scores were 58% and 52%. A single score for each of the seven attributional dimensions was also calculated for each staff carer. This was obtained by dividing their total score on each attributional dimension by the number of rateable attributions contributing to the total score. The results indicated that staff carers' causal attributions tended to be internal, uncontrollable, personal, global and stable to the client and external and uncontrollable by the staff carer. The mean scores on the Carer Coping Style Questionnaire showed that staff carers in this study tended to cope by using the helpful coping styles, such as warmth, reassurance and constructiveness, and not by using the unhelpful coping styles, such as criticism/coercion, collusion, passive, resignation, emotional overinvolvement or overprotectiveness.

**Table 1.** Mean scores and standard deviations for staff carers on the Knowledge Questionnaire, the ASchizQ attributional dimensions and the CCSQ sub-scales.

	MEAN	SD
Total Knowledge Score	9.35	2.99
Internal-External (Client)	4.64	1.38
Controllable-Uncontrollable (Client)	4.61	1.25
Personal-Universal (Client)	3.77	1.60
Global-Specific (Client)	5.52	1.10
Stable-Unstable (Client)	5.89	1.28
Internal-External (Carer)	2.19	0.88
Controllable-Uncontrollable (Carer)	4.50	1.53
Internal, Controllable-External, Uncontrollable (Client)	3.95	0.93
Internal, Controllable-External, Uncontrollable (Carer)	2.84	0.92
Criticism/coercion	2.29	0.59
Collusion	2.34	0.55
Resignation	2.16	0.50
Passive	2.67	0.57
Emotional overinvolvement	2.29	0.61
Overprotectiveness	2.67	0.54
Warmth	4.00	0.55
Reassurance	4.08	0.40
Constructive	3.80	0.44

## ***Relationship between Situational Variables and Causal Attributions***

Pearson correlation coefficients were computed between the situational variables and each of the seven attributional dimensions (see Table 2). In this paper, a 1% level of significance was set in order to reduce the number of type one errors. No statistically significant differences were found between these variables. However, there was a trend for staff carers to make causal attributions, which were more uncontrollable by the client, if they had received training and/or support for schizophrenia or mental health issues. There was also a trend for male staff carers to make attributions, which were more personal to the client.

**Table 2.** Correlations between situational variables and the ASchizQ attributional dimensions.

	Knowledge Questionnaire	Support or Training for Mental Health Problems or Schizophrenia	Gender of staff carer	Age of client
Internal-External (Client)	0.11 (0.45)	-0.15 (0.31)	0.18 (0.24)	0.10 (0.53)
Controllable-Uncontrollable (Client)	-0.08 (0.61)	0.32* (0.03)	0.06 (0.71)	0.11 (0.47)
Personal-Universal (Client)	-0.31 (0.84)	0.17 (0.27)	-0.33* (0.02)	-0.05 (0.75)
Global-Specific (Client)	0.06 (0.71)	0.02 (0.90)	-0.22 (0.15)	-0.01 (0.97)
Stable-Unstable (Client)	-0.02 (0.88)	-0.06 (0.70)	-0.14 (0.35)	-0.23 (0.12)
Internal-External (Carer)	0.02 (0.92)	0.19 (0.20)	0.04 (0.81)	-0.06 (0.68)
Controllable-Uncontrollable (Carer)	-0.17 (0.25)	-0.26 (0.08)	-0.05 (0.75)	-0.10 (0.49)

\* Correlation is significant at the 0.05 level (2-tailed)

## ***Relationship between Causal Attributions and Coping Styles***

Pearson correlation coefficients were then computed between the each of the seven attributional dimensions and the coping sub-scales, in order to explore the relationship between these groups of variables (see Table 3). The results indicated three statistically significant findings. External and uncontrollable attributions to the staff carers themselves were statistically significantly correlated with higher scores on the emotional overinvolvement coping scale. Staff carers' uncontrollable attributions were also statistically significantly correlated with higher scores on the resignation coping scale. There was also a trend for internal attributions to the client to be correlated with a higher score on the emotional overinvolvement coping scale and a trend for stable attributions to be correlated with a higher score on the criticism/coercion coping scale.

**Table 3.** Correlations between the ASchizQ attributional dimensions and CCSQ subscales.

	Internal (Client)	Controllable (Client)	Personal (Client)	Global (Client)	Stable (Client)	Internal (Carer)	Controllable (Carer)
Criticism/coercion	-0.09 (0.54)	0.14 (0.36)	0.13 (0.38)	-0.12 (0.42)	0.30* (0.05)	0.13 (0.38)	-0.08 (0.62)
Emotional overinvolvement	0.33* (0.03)	0.03 (0.85)	-0.11 (0.48)	0.19 (0.20)	0.08 (0.60)	-0.38** (0.01)	0.47** (0.00)
Warmth	0.04 (0.79)	0.22 (0.15)	0.11 (0.48)	0.08 (0.59)	0.08 (0.62)	0.10 (0.50)	-0.07 (0.65)
Collusion	-0.08 (0.60)	-0.07 (0.63)	0.17 (0.26)	-0.11 (0.45)	-0.03 (0.84)	-0.10 (0.51)	0.14 (0.36)
Resignation	0.27 (0.07)	0.03 (0.87)	0.02 (0.91)	0.03 (0.84)	0.25 (0.09)	-0.16 (0.28)	0.45** (0.00)
Passive	0.08 (0.58)	-0.04 (0.79)	0.13 (0.38)	-0.24 (0.11)	0.12 (0.44)	0.16 (0.29)	0.25 (0.10)
Constructive	-0.04 (0.80)	-0.04 (0.80)	0.12 (0.43)	0.19 (0.21)	0.10 (0.53)	0.06 (0.70)	-0.25 (0.10)
Reassurance	0.03 (0.83)	-0.02 (0.91)	0.05 (0.76)	0.03 (0.84)	0.08 (0.59)	-0.01 (0.94)	-0.07 (0.65)
Overprotectiveness	0.21 (0.16)	-0.10 (0.51)	0.10 (0.52)	0.05 (0.74)	-0.04 (0.81)	-0.18 (0.24)	0.14 (0.36)

\* Correlation is significant at the 0.05 level (2-tailed) \*\*Correlation is significant at the 0.01 level (2-tailed)

## ***Hypothesis Testing***

In order to test the hypotheses, two new attributional dimensions were created. This involved summing the internal-external and controllable-uncontrollable attributional dimensions for both clients and staff carers. Higher scores on these dimensions indicated greater internal, controllable attributions. The means and standards deviations of these attributional dimensions are shown in Table 1 (see internal, controllable-external, uncontrollable attributions).

Pearson correlation coefficients were then computed between the new attributional dimensions and the coping sub-scales. None of the hypotheses were confirmed. There were no significant correlations between the internal, controllable attributional dimension for the clients' cause and any of the helpful or unhelpful coping styles. The third hypothesis stated that internal, controllable attributions to the staff carers themselves would be significantly positively correlated with the emotionally overinvolved and overprotective coping scales. Contrary to the hypothesis, the results indicated that external, uncontrollable attributions to the staff carer were significantly correlated with higher scores on emotional overinvolvement coping scale. This pattern of attributions was also significantly correlated with higher scores on the resignation coping scale.

**Table 4.** Correlations between internal, controllable attributions and the CCSQ subscales.

	Internal, Controllable – External, Uncontrollable (Client) <i>n</i> = 46	Internal, Controllable – External, Uncontrollable (Staff Carer) <i>n</i> = 46
Criticism/coercion	-0.20 (0.18)	0.13 (0.20)
Emotional overinvolvement	0.25 (0.09)	-0.57** (0.00)
Warmth	-0.12 (0.42)	0.11 (0.24)
Collusion	-0.01 (0.98)	-0.17 (0.14)
Resignation	0.21 (0.16)	-0.45** (0.00)
Passive	0.13 (0.40)	-0.13 (0.20)
Constructive	0.01 (0.98)	0.24 (0.06)
Reassurance	0.05 (0.73)	0.05 (0.37)
Overprotectiveness	0.19 (0.20)	-0.20 (0.09)

\*\* Correlation is significant at the 0.01 level (2-tailed)

## Discussion

The present study does not find support for the hypotheses. However, it has identified some unexpected yet interesting relationships between staff carers' causal attributions and their coping styles. Contrary to the hypotheses, the results show a significant correlation between external and uncontrollable attributions about staff carers' own role in the cause of symptoms associated with a diagnosis of schizophrenia and emotionally overinvolved and resigned coping styles. These attributional dimensions might be interpreted as reflecting the underlying feelings of helplessness and hopelessness, which may be experienced by these staff carers. The emotional quality of the relationship represented by the emotionally overinvolved coping style appears to mirror the difficulties that staff carers frequently reported in coping with the clients'

behaviour. Whereas, higher levels of resignation seems to reflect the staff carers' perceptions that such behaviours are inevitable and that any action that they take will not have any affect.

The results provide some evidence that staff carers' causal attributions may play a role in determining their coping styles. It was surprising that the results did not show any significant correlations between staff carers' attributions about the clients' role in the cause of the symptoms associated with a diagnosis of schizophrenia and either helpful or unhelpful coping styles, as predicted in the hypotheses. However, the results indicated a number of trends. Higher scores on the emotional overinvolvement coping style was correlated with making attributions that were more internal to the client, higher scores on the criticism/coercion coping scale was correlated with making more stable attributions and male members of staff tended to make attributions that were more personal to the client.

The lack of hypothesised relationships between these variables might be due to a number of factors. It is possible that the small number of staff carers recruited during the course of the study, which was inevitably constrained by a relatively small population of individuals with a mild learning disability and a diagnosis of schizophrenia, limited the statistical power of the analysis. There were also a number of methodological differences between this research and related studies in learning disability and schizophrenia fields. In schizophrenia research, the Camberwell Family Interview (CFI; Vaughn & Leff, 1976b) is used to measure extreme coping responses, such as criticism, hostility and emotional overinvolvement (see Brewin et al. 1991; Barrowclough et al. 1994; Weisman et al. 1993). However, staff carers' coping responses in the current study were measured by the CCSQ (Budd et al. 1998). The results of the CCSQ indicated

that the majority of this group of staff appear to be coping effectively with the potential demands of working with this client group, with few staff scoring highly on the unhelpful coping scales, such as criticism/coercion. This might reflect the fact that paid carers may be less emotionally attached to their clients as their relationships are limited to the bounds of paid work (see Barrowclough et al. 2001). However, it might also reflect difficulties that staff carers experience in sharing undesirable thoughts or behaviours related to the client that they care for and a tendency for them to answer in ways which might be seen as more socially acceptable (social desirability). Therefore, it might be possible that the relationship found between relatives' attributions and their coping responses towards patients with schizophrenia might be limited to the extreme coping responses, which are captured by the CFI.

There may also be a range of variables not included in this study, such as the perceived severity of psychotic symptoms, different types of symptoms or behaviours, clinical intervention programmes or more informal aspects of the service culture, such as unwritten rules developed by staff working together, which may well influence staff carers attributions and consequently their coping responses (see Hastings, Remington & Hopper, 1995; Stanley & Standen, 2000). It is also possible that there are significant differences in the way different carers of different client groups react to challenges. For example, Sharrock et al. (1990) suggested that care staff in psychiatric settings might be faced with a high frequency of difficult to manage behaviours, which raised the possibility that some staff may habituate to them. Therefore, the staff carers in the current study may have learnt not to be significantly influenced by their cognitive or emotional reactions to their clients' behaviour.



Despite these limitations, the findings may have important clinical implications for both staff carers and for client outcomes. The attributional relationship with both emotionally overinvolved and resigned coping styles might not represent increased stress levels within the caring environment, which might increase the likelihood of relapse, but may serve to maintain symptoms in the longer term (see Barrowclough et al. 1994). It seems that increasing staff carers' own personal sense of control over clients' symptoms or behaviours and supporting them to reattribute the cause of the problems to factors, which are more external to the client, might help to reduce emotional overinvolvement and resignation. This type of approach would need to be assessed on an individual level (see López et al. 1999) and would be dependent upon context, as staff may have more control over some behaviours than others.

The relationship between stable attributions and the criticism/coercion coping scale may have negative consequences for clients' progress, particularly because criticism is the element of EE, which has been found to contribute most to the correlation between EE and relapse (Hooley 1998). Also there was a tendency for male members of staff to make more personal attributions to the client. Research evidence links personal attributions with hostile and critical coping responses (e.g. Brewin et al. 1991; Barrowclough et al. 1994). Therefore, male rather than female staff carers may be at greater risk of developing these types of unhelpful coping responses towards individuals with a dual diagnosis. The development of clinical interventions designed to change staff carers' beliefs about the causes of schizophrenia and associated symptomatology may help to decrease unhelpful coping strategies. This may be important because such unhelpful coping strategies may have negative consequences for staff carers' psychological well-being and for clients' outcome.

It is also clear from previous research (e.g. Quigley et al. 2001; Prosser, 1999) and from the current study that few staff carers receive appropriate training about psychosis and have a low level of formal knowledge about schizophrenia. The present findings also indicate a trend for staff that have received training or support for schizophrenia or mental health problems to make causal attributions, which were perceived as being more uncontrollable by the clients. This may have important clinical implications for training initiatives, as this type of attribution has been associated with coping, which reflects greater patience, understanding and tolerance, which is thought to contribute to less stress and a more favourable outcome (e.g. Hooley, 1987). Therefore, the development, implementation and evaluation of a range of psychosocial training initiatives for staff caring for individuals with a learning disability and a diagnosis of schizophrenia appears to be a priority. This might involve an educational component and ongoing support to help staff carers to manage psychotic symptoms in the longer term. These types of interventions might enhance staff carers' confidence in their ability to cope with psychotic symptoms and help them to develop their client's potential and quality of life in the future. However, it must be pointed out that the interventions highlighted also have significant implications for the development of multi-disciplinary services for this client group and their carers.

Due to the small sample size, the present research findings and clinical implications need to be treated cautiously and need to be replicated with larger numbers of participants. Further research should focus on developing a better understanding of the influence of staff carers' causal attributions on a range of coping responses. However, it also seems that future research might benefit from exploring a more complex picture of the experience of caring for individuals with a dual diagnosis. This might involve examining a range of other variables

on staff carers' cognitive, emotional and behavioural responses to clients who have a dual diagnosis, such as, the perceived severity of psychotic symptoms, different types of symptoms or behaviours, including positive and negative symptoms (Hooley, 1987) and more externally directed behaviours, such as aggressiveness or destructiveness (Stanley & Standen, 2000), and the formal and informal aspects of the service culture. It might also be useful to test Weiner's (1980, 1986) attribution model of helping behaviour more directly by including a measure of staff carers' affective responses, which has been undertaken in other learning disability settings (e.g. Dagnan et al. 1998; Standen and Stanley, 2000).

This research study adopted a cross-sectional and correlational design, which makes it difficult to interpret the direction of the relationship found between staff carers attributions and their coping styles. Therefore, longitudinal research is needed to examine these relationships over time. Finally, considering the significant body of literature, which shows that the course and outcome of schizophrenia is highly responsive to the psychosocial environment and emotional atmosphere within the family (see Wearden et al. 2000) it seems important to continue to pursue similar lines of research with staff carers and individuals with a dual diagnosis.

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## **Chapter Four**

### **Research Review**

This paper describes some of my experiences and observations of conducting research with staff carers of individuals with a learning disability and a diagnosis of schizophrenia.

My interest and motivation to undertake a piece of research in this field came from my experience of working as an Assistant Psychologist with individuals who suffered severe and enduring mental health difficulties. During this time I came across a number of people who also had a learning disability and were referred to the Clinical Psychology Service, either for individual therapy or for support for the staff team. I was also aware that there was a limited amount of psychological research being carried out with this client group, which included the education groups and early warning signs interventions in North Warwickshire and a cognitive-behavioural therapy trial for individuals with a mild learning disability and psychosis.

My original research ideas developed from my interest in working with individuals with learning disabilities who reported voice-hearing experiences. I considered designing a semi-structured questionnaire and using a qualitative methodology to explore individuals' experiences of their voices. I also thought about developing a cognitive-behavioural intervention for a small number of clients who heard voices (see Chadwick et al., 1996). However, when I was developing my research protocol, there were few clients reporting these experiences in North Warwickshire and there was limited, if any, academic supervision for qualitative research. As a consequence, I became interested in the research and clinical literature concerning the relationship between the emotional atmosphere within families and relapse rates of individuals with a diagnosis of schizophrenia, with the view to undertaking a similar quantitative study with individuals with learning disabilities and their carers. I was also drawn to the application of attribution theory to the understanding of carers' coping responses because of the potential to inform the development of cognitive-

behavioural interventions for carers of individuals with learning disabilities (see Kushlick et al. 1997), which guided the current study.

Despite being aware of the problems inherent in the diagnosis of schizophrenia, the strong arguments which question the reliability, validity and utility of the concept and the debate surrounding its existence or non-existence (see Birchwood & Jackson, 2001; Boyle, 2002; Boyle, 1996; Pilgrim, 2000; Stenfert Kroese et al. 2001) I was not as sceptical about the concept as I perhaps should have been at the beginning of the research process. I adopted the 'syndrome view of schizophrenia' as a way of recruiting people with learning disabilities suffering from 'psychotic' experiences and their carers and used it to develop the research methodology in order to examine staff carers' experiences of working with this client group.

Throughout this research review I intend to reflect on my own experiences of conducting research in this field and my concerns about the concept of 'schizophrenia', which will highlight the difficulties with making psychiatric diagnoses with individuals with learning disabilities. However, in doing this I do not want to lose sight of the distressing and disturbing experiences and behaviour that these individuals can suffer from and the challenges and potential stresses for their carers, which was the focus my study. I also want to use this review to consider how this research might influence my clinical and research practice in the future.

### **Ethical Issues**

Given that one of the limitations of previous attributional research in the learning disabilities literature was that carers' responses were related to theoretical rather than real-life events (e.g. Dagnan et al. 1998; Stanley & Standen, 2000), I developed my research study to examine the relationship between carers'

attributions and their coping styles in real life practice. It was important to me that the individuals with a dual diagnosis of a mild learning disability and schizophrenia received appropriate information about the research project and were able to make a decision about whether their carers should participate in the study.

I used a number of resources to develop a booklet (see Appendix E) in order to share information about the research project with these individuals. These included, general guidelines provided by Coventry and Warwickshire Research Ethics Committees for the development of information sheets, research highlighting methods for addressing and gaining consent to psychological research by people with a learning disability (e.g. Freedman 2001; Arscott et al. 1998), and the Protocol and Record of Assessment of Client's Capacity to Make a Decision developed by Brooklands Multidisciplinary Consent Working Party, North Warwickshire NHS Trust (1998/2000) (see Appendix G). I aimed to produce a booklet with information, which was clear, concrete and non-threatening. I attempted to make the language as simple as possible and used a range of pictures and symbols to support the written information. I had expected to use the booklet flexibly, dependent on the needs of each individual and had not really anticipated any difficulties gaining consent from this group of individuals.

However, my experiences of gaining consent varied greatly and have highlighted a number of the challenges involved in undertaking research in this field. I was aware that some individuals might agree to participate, acquiesce (e.g. Sigelman et al. 1981), without fully understanding the information that was being shared. Therefore, a number of measures were taken to try to overcome these issues, including seeking the help of a staff carer who knew the person well to help explain the research project, which I found invaluable. However, many of these carers were later involved in the research process themselves. This highlighted the importance

of trying to ensure that the individuals' consent was voluntary, without any pressures to take part from either the researcher or from the staff carer. It also stressed the potential value of using independent advocates in future research to present information and discuss the advantages and disadvantages of research with individuals with learning disabilities. It also highlighted much wider issues about the limited opportunities that individuals with learning disabilities have to make choices on a day-to-day basis and the need to educate people about their rights so that they can make decisions affecting their lives.

I had also not anticipated the amount of time that would be required to gain informed consent. I offered between two and five appointments for each individual to share the information about the research, which involved adapting and simplifying the information booklet to meet individuals' needs, where necessary. I also used a range of prompt questions to ascertain if individuals understood the information provided. In retrospect, it would have been useful if these questions had been formalised and then used to assess the ability of these individuals to consent to their carers taking part in the research (e.g. Arscott et al. 1998). This would have helped to guide my own decision making about the amount of information that each client was able to understand and would have also contributed to the body of research in this area. On two occasions it was extremely difficult to gain informed consent from the client and opinion was sought from the Consultant Psychiatrist, Home Manager and family members to make a decision on the client's behalf.

Finally, despite the debate surrounding the concept of schizophrenia and the complications of diagnosing people with learning disabilities, the individuals recruited during the process of this research study had already received this diagnosis. However, it was worrying that only a third of them appeared to recognise or have any understanding of what the word 'schizophrenia' meant to them. This

highlighted the potential ethical and clinical implications regarding their understanding and consent to psychiatric treatment. This is of particular concern when many of these individuals appeared to be on a 'cocktail' of medication.

### **The Research Process**

To obtain a representative sample of staff carers of individuals with a learning disability and a diagnosis of schizophrenia, I recruited participants through Consultant Psychiatrists. The response rates were initially extremely low and I experienced significant anxieties about being able to recruit enough participants. Also, the actual process of recruiting participants; organising appointments with staff, attending staff meetings to talk about the research project, gaining consent and explaining and collecting questionnaires was an exhausting process. This required a significant amount of time and similar levels of perseverance, motivation and determination, which I am sure contributed to the eventual good response rate.

I also envisaged that it would be difficult to engage staff carers in the research process. However, most people I approached were interested and happy to take part. Many carers said that they had enjoyed completing the questionnaires because it gave them an opportunity to reflect on their own experiences. The staff carers were often very open about their experiences of caring for these individuals and responded by giving me additional information about the person that they were currently caring for. They shared many of the challenges and stresses related to caring for the person with a learning disability and a diagnosis of schizophrenia, which were not always included within the research protocol. Some of these were, ongoing concerns about an individual who bought toy guns and would use them to threaten people in the street, individuals who would continually pace around the home, become easily irritated and agitated, and staff carers' difficulties



understanding whether certain behaviours might be indicative of 'psychotic' experiences, such as individuals mumbling to themselves, shouting back at people not present, and saying that people were out to get them.

One of the earlier aims of the research had been to compare groups of family and staff carers. Although I was unable to recruit enough family members, five relatives did take part (two mothers, two fathers and a husband). Meeting with these family members and having the opportunity to learn about their experiences of caring for their family member was very insightful. They shared a number of events, which elicited strong emotions for them, such as the stresses and burdens of providing 24-hour care, the limited access to professional support, the stigma associated with a diagnosis of schizophrenia and their ongoing search for an explanation of their family members difficulties. In some cases this seemed to be linked with self-blaming attributions about the cause of schizophrenia. Unsurprisingly, these experiences were very different from those shared by the staff carers. This highlighted the need for future research to explore the needs of both relative and staff carers and to develop appropriate services for these different groups of carers.

Some of the examples that staff gave about their experiences of caring for this client group reflected the problems that these and other professional carers have identifying 'true' hallucinations and delusions in individuals who also have a learning disability. This is not surprising, particularly when some of these clients would certainly have difficulties finding the language needed to describe the complex and abstract nature of the potentially distressing and disturbing experiences and emotions that they might be suffering from (see Reid, 1972). An example from my experience of conducting this research involved observing a man who frequently shouted and screamed at someone or something that was not there. After meeting with him on several occasions, it became clearer that his experience and behaviour

seemed to have a variety of different meanings or functions, which led me to question whether he was experiencing 'psychotic' phenomena. This highlighted the importance of thorough assessments and formulations of clients needs in order to better understand their obvious psychological distress, which reflects my clinical practice. In terms of my psychological work in the future, I will continue to find ways to explore and understand the content, meaning and function of 'psychotic' experiences and behaviours of individuals that I work with.

Based on the literature related to the phenomenon of 'diagnostic overshadowing' (Reiss, Levitan & Szyszko, 1982; Reiss & Szyszko, 1983) and schizophrenia research, which highlights attributional differences between positive and negative symptoms (Hooley, 1987), I had expected staff carers to attribute the less recognisable 'psychotic' symptoms to the individuals' learning disability. However, in response to the open-ended question on the Attributions for Schizophrenia Questionnaire (ASchizQ), 'What do you think is the main cause of these experiences?' staff carers' generated 169 causes, only two of these mentioned the individuals' learning disability. These staff generated a wide range of causes, which have been grouped into five main themes and are summarised in Table 1. The variety of these causes seemed to reflect the problems that staff carers disclosed in understanding the individuals' difficulties. However, they also highlight the importance of other variables in understanding the complexity of individuals' experiences, which is not accounted for by a psychiatric diagnosis. These findings have significant implications for the development of multi-disciplinary services for this client group and their carers. This is particularly important as the sole professional support for the majority of individuals in this study was from their Consultant Psychiatrist.

**Table 1** Main themes, descriptions and examples of causal attributions generated by staff carers in response to the ASchizQ.

MAIN THEMES	EXAMPLES OF THEMES	PERCENTAGE & NUMBER OF RESPONSES
<b>Environmental Causes:</b> included reference to aspects of the individuals and their environment.	'Crowded places/spaces' 'Change in routine due to staff support' 'Moving to a residential home with eight other people'	5.3% <i>n</i> = 9
<b>Personality Causes:</b> included reference to characteristics of the individuals' personality.	'I think he is a loner' 'It's her. She's lazy' 'His character'	4.1% <i>n</i> = 7
<b>Interpersonal Causes:</b> included reference to aspects of the way the individual communicated or related to other people.	'Changing the direction of conversation' 'When he wants something' 'Difficulties in relating to people'	11.2% <i>n</i> = 19
<b>Psychological Causes:</b> included reference to the emotional or mental state of the individual.	'Anxiety' 'Boredom' 'Preoccupied or confused about things going on in his head'	37.9% <i>n</i> = 64
<b>Psychiatric/Medical Causes:</b> included reference to a psychiatric illness, the symptoms or treatment of the illness or some other medical cause.	'Schizophrenia' 'Hearing voices' 'Change in medication'	37.3% <i>n</i> = 63
<b>Miscellaneous Causes:</b> causes, which were not coded.	'Maybe to scare me as I was new to the job' 'Death of her Dad'	4.1% <i>n</i> = 7

## Methodological Issues

I have questioned the validity of the methodology that I chose for my research. I felt that a more qualitative approach would have been a more appropriate method for examining the current and future psychological needs of this group of staff carers. This would have provided a more in-depth exploration of their experiences of caring for this client group.

Furthermore, in adopting a quantitative methodology for this research study, appropriate questionnaires to measure the variables chosen for the study did not exist in the learning disabilities literature. Therefore, some of the questionnaires used in this study had to be developed or adapted for the purposes of the research, and may require further development in the future.

Also, based on the staff carers' reports about their experiences of working with this client group, I questioned whether the ASchizQ tapped into those behaviours which were the most stressful or challenging for this staff group at the time of the research. As a result I have wondered whether the limited relationships found between the variables studied might be related to the nature of the behaviours and experiences, which were examined by this attributional measure.

### **Personal Reflections and Learnings**

I was motivated to undertake a piece of research in a new area, which interested, excited and challenged me. During this process I have experienced a number of problems relating to the limitations of undertaking research in this field. This has caused me anxieties about achieving my aims and ultimately a sense of disappointment about the results of the study. It has also been very demanding and stressful undertaking a large-scale clinically based research project whilst also being on clinical placement and attending University.

Nevertheless, I have learnt a great deal about research throughout this process, including the formation of research ideas, the development of questionnaires, experience of ethical committees, recruitment of a clinical population and statistical analysis. These experiences have enabled me to feel more confident in my ability to consume, utilise and produce research. I intend to maintain and develop these skills

during my career as a Clinical Psychologist. I am able to understand research papers, critically evaluate them and apply their findings to inform the development of my clinical practice. I am motivated to continue to learn how to evaluate my own work and that of psychological services, and intend to report these findings in appropriate scientific journals. Finally, I am keen to pursue new and interesting research opportunities in the future.

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## Appendix A

Warwickshire   
Health Authority

Our Ref : \PAH  
Your Ref :

15th June 2001

Westgate House  
Market Street  
Warwick CV34 4DE

Tel: 01926 493491  
Fax: 01926 495074

Ms Tracey Parslow,

Dear Tracey,

**Warwickshire Research Ethics Committee**

**LREC 482 Carers of individuals with learning disabilities and a dual diagnosis of schizophrenia : Carers coping style distress attributions and knowledge about schizophrenia**

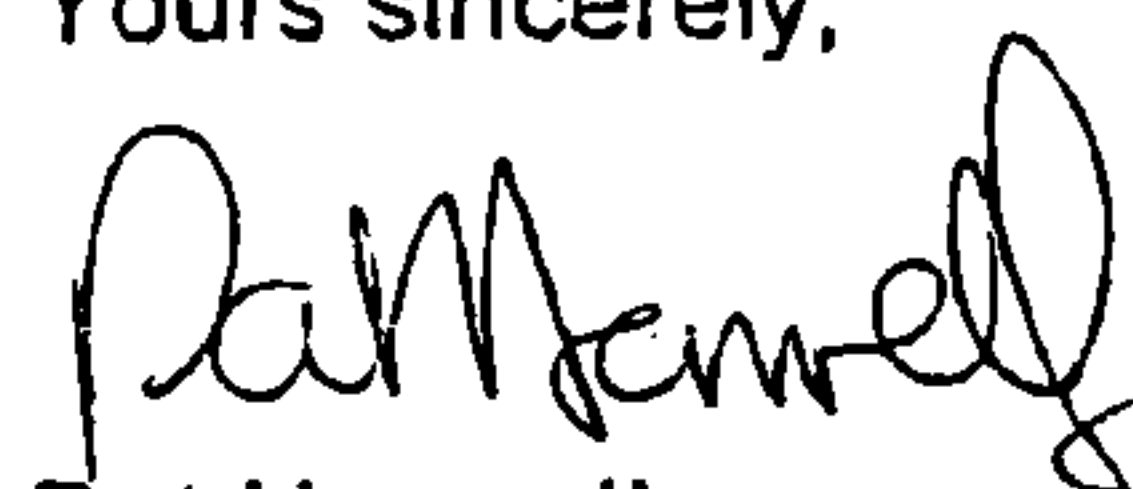
Thank you for your recent submission for the above study which has been approved and your certificate is enclosed.

I give below the observations and comments made at the meeting which you agreed to adopt :

- ❖ PIS add All other Carers 'in a similar situation'
- ❖ explanation to be in lay person terms e.g. replace dual diagnosis

If you have any queries please do not hesitate to contact me.

Yours sincerely,



Pat Horwell  
Administrator  
Warwickshire Research Ethics Committee

Please quote where possible reference either RE... or MREC ... on all correspondence as this will help in delivering a speedy reply



PAH  
12<sup>th</sup> June 2001

Westgate House  
Market Street  
Warwick CV34 4DE

Tel: 01926 493491  
Fax: 01926 495074

**WARWICKSHIRE RESEARCH ETHICS COMMITTEE**

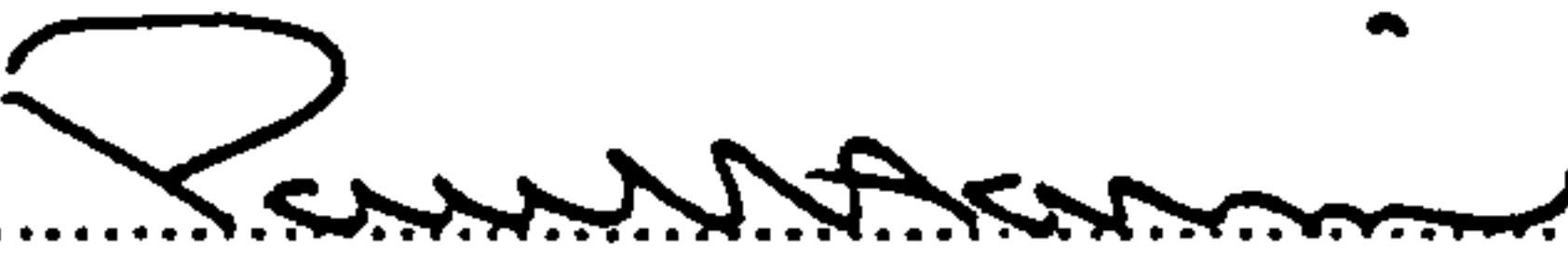
The following LREC trial protocol has been examined from an ethical viewpoint and the decision of the Committee is as follows:

		<b>Documentation Reviewed as itemised in ICH guidelines</b>	
1.	* Approved	<b>Protocol</b>	<input checked="" type="checkbox"/>
		<b>Patient Information Form/ Consent Form</b>	<input checked="" type="checkbox"/>
2.	Approved subject to amendments listed below	<b>Indemnity (signed) CTX</b>	<input checked="" type="checkbox"/>
		<b>Protocol Amendments</b>	<input type="checkbox"/>
3.	Rejected for reasons listed below		
4.	Approved by Chairman's Action		

**Ethical Committee Minute Number 534/01 Dated 30<sup>th</sup> May 2001**

**Protocol Title and Reference Number**

**RE 482 Carers of individuals with learning disabilities and a dual diagnosis of schizophrenia : Carers coping style distress attributions and knowledge about schizophrenia**  
(Tracey Parslow)

Signed..........Committee Chairman

Dated.....13/6/01.....

This approval is subject to the following standard conditions :

1. the study must begin within one year;
2. the researcher must seek the Committee's approval in advance of any Proposed deviations from the original protocol;
3. any unusual or unexpected results which raise questions about the safety of the study must be reported to the Committee.
4. progress reports must be submitted to the Committee annually; and
5. a summary of the study's findings must be submitted to the Committee upon its Completion.

Warwickshire Research Ethics Committee

Meeting held on Wednesday 30<sup>th</sup> May 2001

MEMBERS PRESENT:

Mr. P. Hamilton (Chairman)

Rev'd D. Johnson, Health Scientist

Dr. M. Graveney, Consultant in Public Health

Dr. H. Brittain, Psychologist

Dr. M. Waltzman, Consultant Physician

Cllr Bill Lowe, CHC

Mrs. V. Rizk, Lay Member

AGM/PJP

Ms Tracy Parslow

Coventry Health Authority  
Christchurch House  
Greyfriars Lane  
Coventry  
CV1 2GQ

Telephone: 024 7655 2225  
Facsimile: 024 7622 6280

10 May 01

**Please reply to**  
Administrative Office, Coventry Research  
Ethics Committee, University Hospitals  
Coventry & Warwickshire NHS Trust,  
Clifford Bridge Road, Coventry CV2 2DX  
Telephone: 024 7653 5219  
Fax: 024 7653 5168

Dear Ms Parslow

**Reference 7.01/05/01 – Please quote this reference number on all future correspondence.**

**Carers of Individuals with a Learning Disability and a Dual Diagnosis of Schizophrenia: Carers' Attributions, Coping Styles, Distress and Knowledge about Schizophrenia. (Tracy Parslow, Student - Warwick & Coventry Universities) Study, Not Sponsored.**

Thank you for the above study, which we have found to be well prepared. However, we would ask that you slightly modify the Participant Information Sheet to reassure participants, as there are several questionnaires, that these are not "daunting".

We look forward to your early response.

Yours sincerely

  
DR A G MORRIS  
VICE CHAIRMAN  
COVENTRY RESEARCH ETHICS COMMITTEE

Ljsc/ht

Ms Tracy Parslow

Coventry Health Authority  
Christchurch House  
Greyfriars Lane  
Coventry  
CV1 2GQ

21 June 2001

Telephone: 024 7655 2225  
Facsimile: 024 7622 6280

**Please note:**

Please reply to Administrative office, Coventry  
Research Ethics Committee, (Former School of  
Nursing), University Hospital Coventry &  
Warwickshire NHS Trust, Clifford Bridge Road,  
Walsgrave, Coventry CV2 2DX.

Tel/Voice Mail: (024) 7653 5219

Fax: (024) 7653 5168.

NB: Coventry Health Authority is still responsible  
for Coventry Research Ethics Committee.

Dear Ms Parslow

REF: 7.01/05/01

(Please quote this reference number on all future correspondence – if this  
number is not quoted unnecessary delays will occur in processing the  
protocol and any subsequent correspondence).

**Carers of Individuals with a Learning Disability and a Dual-Diagnosis of  
Schizophrenia:**

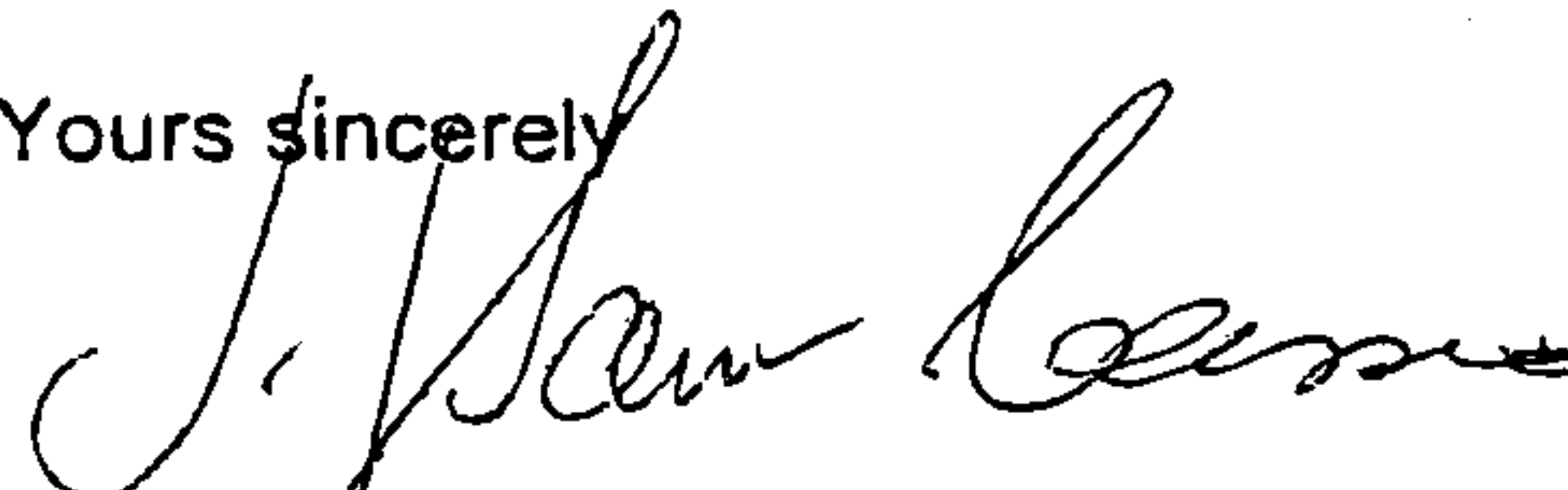
**Carers Attributions, Coping Style, Distress and Knowledge about  
Schizophrenia.**

Protocol not dated.

Thank you for your letter dated 13 June 2001.

I confirm that the modified Patient Information Sheet, which you will have printed on  
Coventry Healthcare NHS Trust headed notepaper, is an acceptable version.

Yours sincerely



L J SANT CASSIA  
CHAIRMAN  
COVENTRY RESEARCH ETHICS COMMITTEE

## Instructions to Authors

Submissions to the *Schizophrenia Bulletin* should be sent to:

### EEI Communications

ATTN: *Schizophrenia Bulletin*  
66 Canal Center Plaza, Suite 2000  
Alexandria, VA 22314-5507

The editors will consider critical reviews of the literature, articles reporting original observations in laboratory or clinical research, short reports of preliminary or negative research reports, workshop reports, first person accounts by patients or family members, and letters to the editor. Photographs of art done by current or former mental hospital patients may be submitted for possible reproduction on the cover of the *Bulletin*; the artist must be willing to grant permission for publication of his or her work, but his or her anonymity will be preserved if he or she wishes.

All materials published in the *Schizophrenia Bulletin* are in the public domain unless otherwise noted.

### Preparation of Manuscript

A detailed set of instructions for manuscript preparation is available from EEI Communications at the address above.

**Text and Tables:** Provide a disk and five copies of the manuscript. Present each table on a separate sheet. Note the table number in the text immediately after the paragraph in which it is described.

**Abstract:** Provide a brief abstract of the manuscript. The abstract should not exceed 175 words in length. Also provide 4-6 words for literature search indexing.

**Review process:** Authors of scientific articles and letters (not first person accounts) should suggest 5 reviewers who are especially qualified to referee the work and who do not have a conflict of interest. In the cover letter, authors should include an area

of expertise, complete address, phone number, fax number, and e-mail (if applicable) for each suggested reviewer. Actual choice of reviewers will be made by the Editor-in-Chief and may or may not include any of the author's suggestions. The Editor-in-Chief may return a submitted manuscript to the author outside review if he deems it to be of insufficient interest to the readership or if there is little likelihood that it will receive favourable review. Editorial rejection is done so that authors may expeditiously submit their articles to a more appropriate journal. All other scientific articles and letters to the editor will be subject to peer review.

**Illustrations:** Submit one copy of each chart, graph, or other illustration in reproducible form (either glossy or computer-generated laser prints). Refer to illustrative materials as text figures. Type the figure number and legend for each on a separate sheet.

**References:** Include a list of all articles and books cited in the text. Arrange alphabetically by major author. When referring to these sources in the text, place the authors' names and date of publication in parentheses immediately after the idea referenced. If more than one source is cited, list in chronological order by date of publication. (If authors' names are used in the same sentence, place only the date of publication in parentheses). Provide page numbers for all quotes. Spell out all journal titles. Bibliographic style should follow that used in articles in this issue.

**Footnotes:** Use footnotes to clarify textual material, and indicate them by superior figures in the text. Insert footnotes as separate paragraphs immediately following the paragraphs in which they are mentioned.

**Author Identification:** Include your own and each author's official title and academic degrees. Specify the address to which reprints should be sent.

**TEXT CUT  
OFF IN  
ORIGINAL**

## Appendix C

### Instructions for Authors

Papers (in English) should be sent to the editors (see address on the inside front cover).

See the journal website  
<http://www.blackwell-science.com/jar>  
for more detailed instructions for authors.

#### Submission

One original and three copies of each typescript should be submitted to one of the editors. Papers are accepted on the understanding that they have not been and will not be published elsewhere.

#### Preparation of the manuscript

Manuscripts should be typed (with a wide margin), double spaced, on one side of standard paper (A4-30x21 cm). Authors should retain one copy of the text, tables and illustrations as the editor cannot accept responsibility for damage or loss of manuscripts. Final versions of accepted manuscripts should be accompanied by disks.

Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

#### Cover page

A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and include postal address, telephone and fax numbers as well as an email address and the author for correspondence should be identified clearly. A suggested running title of not more than fifty characters, including spaces; and up to six key words to aid indexing should also be provided.

#### Main text

All papers should be divided into a structured summary (150 words) and the main text with appropriate sub headings. A structured summary should be given at the beginning of each article, incorporating the following headings: Background, Method, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study.

The text should proceed through sections of Abstract, Introduction, Materials and Methods, Results and Discussion. Tables and figures should be submitted on separate sheets and referred to in the text together with an indication of their approximate position recorded in the text margin. The reference list should be in alphabetic order thus:

Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*.

Cambridge University Press, Cambridge.

McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

#### Illustrations and tables

These should be referred to in the text as Figures using Arabic numbers. e.g. Fig. 1. Fig. 2. etc. in order of appearance.

Three copies of each figure should be submitted and each figure should be marked on the back with its appropriate number, together with the name(s) of the author(s) and the title of the paper. Figures that have been generated electronically should be saved using the 'normal' save process of the software program and also as a PostScript or EPS file.

Line drawings should be on a separate sheet in black ink (dot matrix illustrations are not permitted).

Photographs should be unmounted glossy prints and should not be retouched.

Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained.

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

#### Disks

We would very much like to receive a word-processed file of your manuscript. Include all parts of the text of the paper in a single file. The following points will help us to use it successfully:

- Include all figure legends, and tables with their legends if available.
- The final version of the hard copy and the file on disk must be the same.
- Do not use the carriage return (enter) at the end of lines within a paragraph.
- Turn the hyphenation option off.
- Complete and enclose the File Description Form
- On the File Description Form, specify any special characters used to represent non-keyboard characters.
- Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or fl (German esszett) for (beta).
- Use a tab, not spaces, to separate data points in tables.
- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.
- Where possible, digital versions of your figures should be included on the disk submitted after acceptance. See our Digital Illustration Standards for details at <http://www.blackwell-science.com/electmed/digill.htm>.

#### Copyright

Copyright in any article accepted for the Journal is assigned to BILD (Publications) by the author(s) at the time of acceptance. The author(s) must confirm that at the time of submission that it has not and will not be submitted for publication elsewhere and that copyright will so be assigned if the article is accepted. Once published, the article cannot be subsequently published elsewhere, in full or in part, or be reproduced or transmitted in any form including photocopying and recording without prior permission of BILD. All reasonable requests to reproduce contributions will be considered.

#### Page Proofs

These must be returned to the Production Editor within 3 days of receipt, ideally by fax. Only typographical errors can be corrected at this stage. Major alterations to the text cannot be accepted.

#### Assessment and editing procedure

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

#### Free copies of the journal

The corresponding author of the paper will receive 5 free copies of the issue in which their paper is published. Offprints may be ordered when returning corrected proofs at prices determined by the Publisher.

## Appendix D

### NOTES FOR CONTRIBUTORS

The *British Journal of Clinical Psychology* publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

- \* Papers reporting original empirical investigations;
- \* Theoretical papers, provided that these are sufficiently related to the empirical data;
- \* Review articles which need not be exhaustive, but which should give an interpretation of the state of the research in a given field and, where appropriate, identify its clinical implications;
- \* Brief Reports and Comments (see below).

#### 1. Circulation

The circulation of the Journal is worldwide. There is no restriction to British authors; papers are invited and encouraged from authors throughout the world.

#### 2. Length

Pressure on Journal space is considerable and papers should be as short as is consistent with clear presentation of the subject matter. Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length.

#### 3. Refereeing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinized and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be made aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to a removable front page (and the text should be free of such clues as identifiable self-citations ('In our earlier work...')).

#### 4. Submission requirements

- (a) Four copies of the manuscript should be sent to the Editor (Professor Karin Mogg/ Professor Brendan Bradley, BPS Journals Department, St. Andrews House, 48 Princess Road East, Leicester, LE1 7DR, UK). Submission of a paper implies that it has not been published elsewhere and that it is not being considered for publication in another journal. Papers should be accompanied by a signed letter indicating that all named authors have agreed to the submission. One author should be identified as the correspondent and that person's title, name and address supplied.
- (b) Contributions must be typed in double spacing with wide margins and on only one side of each sheet. All sheets must be numbered.
- (c) Tables should be typed in double spacing, each on a separate piece of paper with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- (d) Figures are usually produced direct from authors' originals and should be presented as good black or white images preferably on high contrast glossy paper, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Paper clips leave damaging indentations and should be avoided. Any necessary instructions should be written on an accompanying photocopy. Captions should be listed on a separate sheet.
- (e) For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: *Objectives, Design, Methods, Results, Conclusion*. Review articles should use these headings: *Purpose, Methods, Results, Conclusions* (more details on Structured Abstracts can be obtained by contacting the Journals Department).
- (f) Bibliographic references in the text should quote the author's name and the date of publication thus: Smith (1994). Multiple citations should be given alphabetically rather than chronologically: (Jones, 1998; King, 1996; Parker, 1997). If a work has two authors, cite both names in the text throughout: Page and White (1995). In the case of reference to three or more authors, use all names on the first mention and et al. thereafter except in the reference list.
- (g) References cited in the text must appear in the list at the end of the article. The list should be typed in double spacing in the following format: Herbert, M. (1993). *Working with children and the Children Act* (pp. 76-106). Leicester: The British Psychological Society. Moore, R.G., & Blackburn, I.M. (1993). Sociotropy, autonomy and personal memories in depression. *British Journal of Clinical Psychology*, 32, 460-462. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.

(h) SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses (see The British Psychological Society *Style Guide* at: <http://www.bps.org.uk/publications/jAuthor.cfm>).

- (i) Authors are requested to avoid the use of sexist language.
- (j) Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

#### 5. E-mail submissions

Manuscripts may be submitted via e-mail. The main text of the manuscript, including any tables or figures, should be saved as a Word 6.0/95 compatible file. The file must be sent as a MIME-compatible attachment. E-mails should be addressed to [journals@bps.org.uk](mailto:journals@bps.org.uk) with 'Manuscript submission' in the subject line. The main body of the e-mail should include the following: title of journal to which the paper is being submitted; name, address and e-mail of the corresponding author; and a statement that the paper is not currently under consideration elsewhere. E-mail submissions will receive an e-mail acknowledgement of receipt, including a manuscript reference number.

#### 6. Brief reports and comments

These allow rapid publication of research studies, and theoretical, critical or review comments with an essential contribution to make. Case studies are normally published only as Brief Reports. They should be limited to two printed pages with the text, including references and a 100 word abstract set at 150 lines. Abstracts should also be structured under these headings: *Purpose, Methods, Results, Conclusions* (more detailed guidelines on structured abstracts are available from the Journals Department). Figures and tables should be avoided. Title, author and name and address for reprints and data of receipt are not included in the allowance. However, deduct three lines from the text each and every time any of the following occur:

- a) title longer than 70 characters
- b) author names longer than 70 characters
- c) each address after the first address
- d) each text heading (these should normally be avoided).
- e) A character is a letter or space. A punctuation mark counts as two characters (character plus space) and a space must be allowed on each side as a mathematical operator.

#### 7. Ethical considerations

The code of conduct of The British Psychological Society requires psychologists 'Not to allow their professional responsibilities or standards of practice to be diminished by consideration of religion, sex, race, age, nationality, party politics, social standing, class or other extraneous factors. The Society resolves to avoid all links with psychologists and psychological organizations and their formal representatives that do not affirm and adhere to the principles in the clause of its Code of Conduct. In cases of doubt, the Journals Department may ask authors to sign a document confirming the adherence to these principles. Any study published in this journal must pay due respect to the well-being and dignity of research participants. The British Psychological Society's Ethical Guidelines on Conducting Research with Human Participants must be shown to have been scrupulously followed. These guidelines are available at: <http://www.bps.org.uk/about/rules5.cfm>

#### 8. Supplementary data

Supplementary data too expensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

#### 9. Proofs

Proofs are sent to authors for correction of print but not for rewriting or the introduction of new material. Fifty complimentary copies of each paper are supplied to the senior author, but further copies may be ordered on a form accompanying the proofs.

#### 10. Copyright

To protect authors and journals against unauthorized reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

#### 11. Checklist of requirements:

- \* A signed submission letter
- \* Correspondent's title/name/address
- \* A cover page with title/author(s)/affiliation
- \* Double spacing with wide margins
- \* Tables/figures at the end
- \* Complete reference list in APA format
- \* Four good copies of the manuscript (or an e-mail attachment)





**INFORMATION BOOKLET**

**CARERS OF PEOPLE WHO HAVE A**  
**LEARNING DISABILITY AND**  
**SCHIZOPHRENIA**

N.B. This was presented as an A5 information booklet

# 1. INTRODUCTION

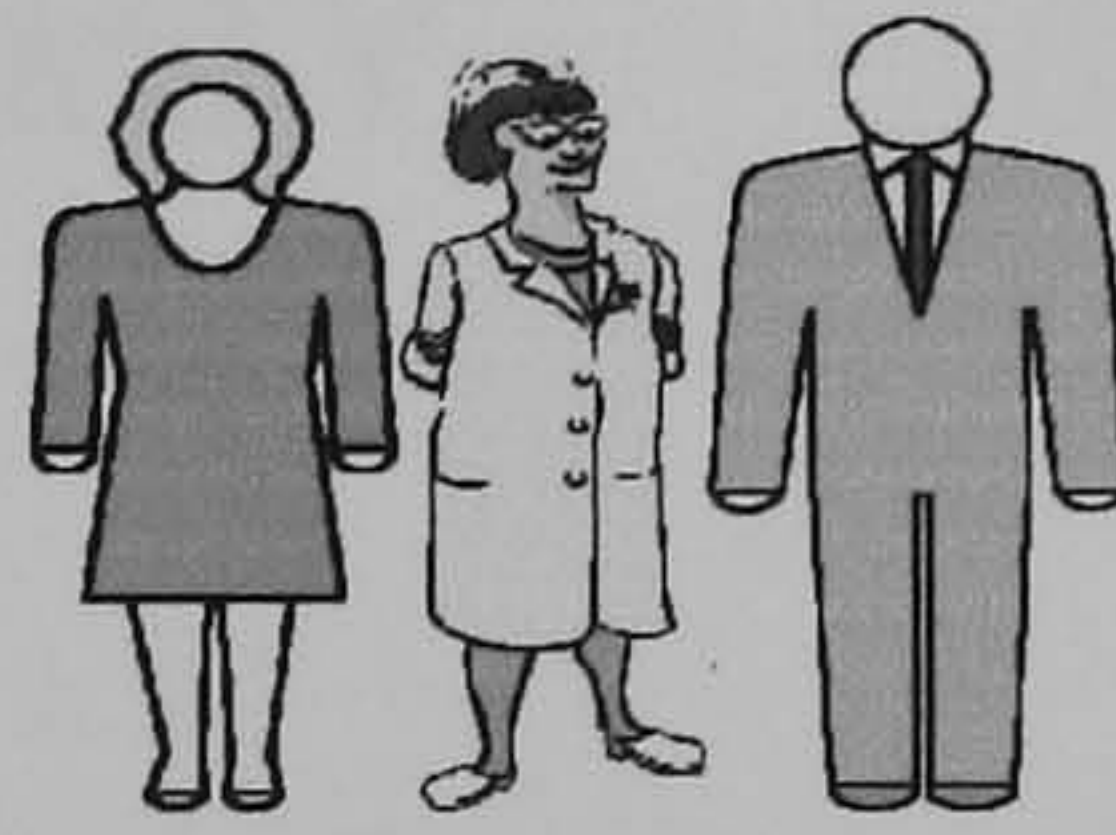
I WANT TO TALK TO YOUR FAMILY OR STAFF  
AND ASK THEM SOME QUESTIONS.



TALK



FAMILY



STAFF



QUESTIONS

THIS INFORMATION BOOKLET WILL TELL YOU  
WHAT QUESTIONS I WANT TO ASK THEM.



INFORMATION  
BOOKLET



QUESTIONS

**YOU CAN TALK TO YOUR FRIENDS, FAMILY OR STAFF ABOUT IT.**



**TALK**



**FRIENDS**



**FAMILY**



**STAFF**

**IF YOU HAVE ANY THOUGHTS OR QUESTIONS PLEASE TALK TO ME (TRACY).**



**THOUGHTS**



**QUESTIONS**



**TALK**



**TRACY**



**THANK YOU FOR YOUR TIME**

2. WHY ASK YOUR FAMILY OR STAFF QUESTIONS?

I WANT TO ASK YOUR FAMILY OR STAFF SOME QUESTIONS ABOUT HOW THEY HELP YOU WHEN YOU FEEL UNWELL, UNHAPPY, SCARED OR WORRIED.



QUESTIONS



UNWELL



UNHAPPY



SCARED



WORRIED

**I AM TALKING TO LOTS OF PEOPLE AND ASKING THEIR FAMILY OR STAFF THE SAME QUESTIONS.**



**TALKING**



**LOTS OF PEOPLE**



**QUESTIONS**

**I HOPE THAT WHAT YOUR FAMILY OR STAFF SAY WILL HELP US TO LEARN HOW TO HELP OTHER PEOPLE LIKE YOU AND THEIR FAMILY AND STAFF BETTER IN THE FUTURE.**



**FAMILY AND STAFF**



**FEEL BETTER**

**3. DO YOU HAVE TO TAKE PART?**

**YOU CAN SAY YES OR NO.**



**YES**

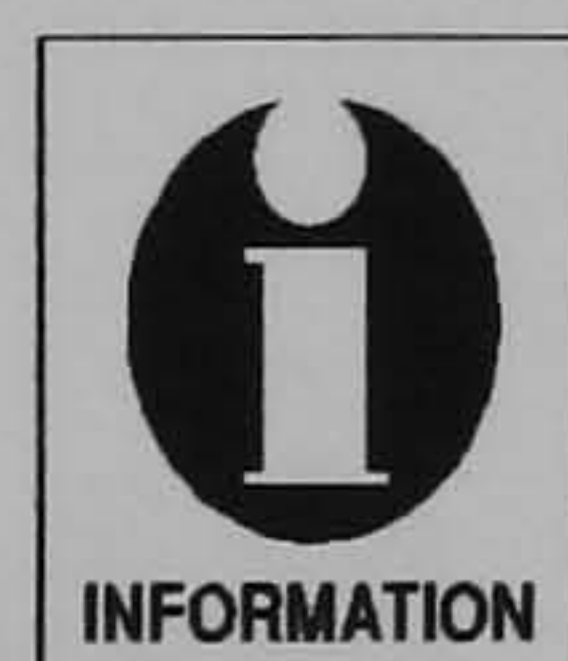


**NO**

**IF YOU SAY YES. I WILL GIVE YOU THIS INFORMATION BOOKLET AND WILL ASK YOU TO SIGN A PIECE OF PAPER – CALLED A CONSENT FORM.**



**YES**

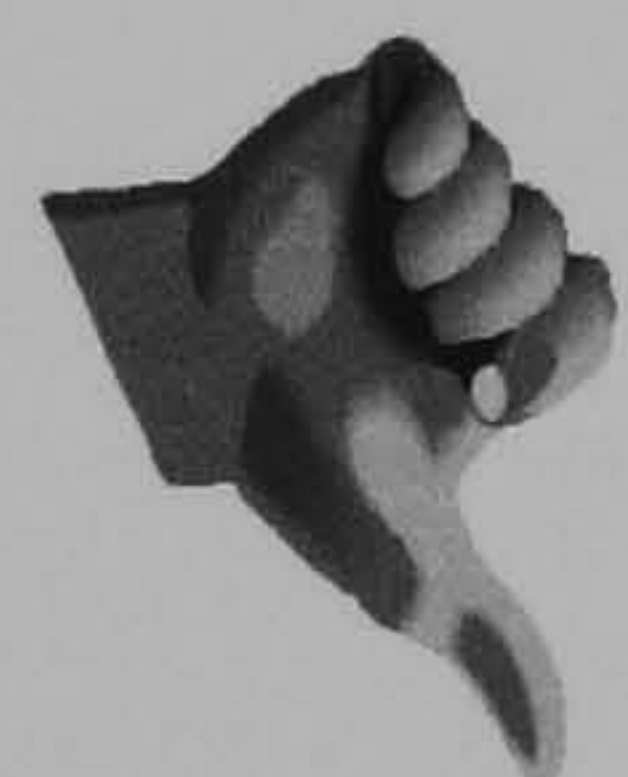


**INFORMATION  
BOOKLET**



**CONSENT  
FORM**

**YOU CAN SAY NO. SAYING NO IS OK.**



**NO**

**=**



**OK**

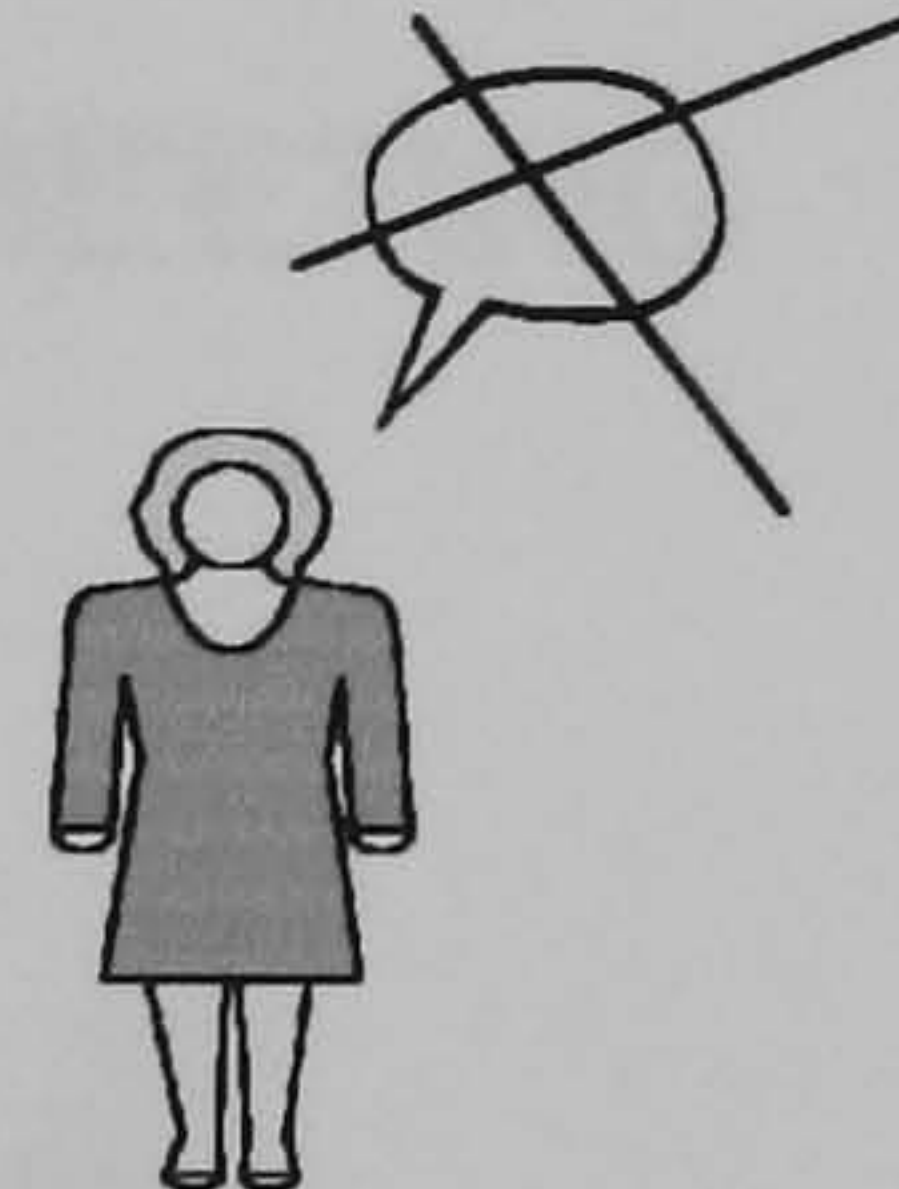
**YOU CAN SAY NO OR STOP AT ANY TIME. YOU DO NOT NEED TO SAY WHY YOU WANT TO SAY NO.**



**NO**



**STOP**

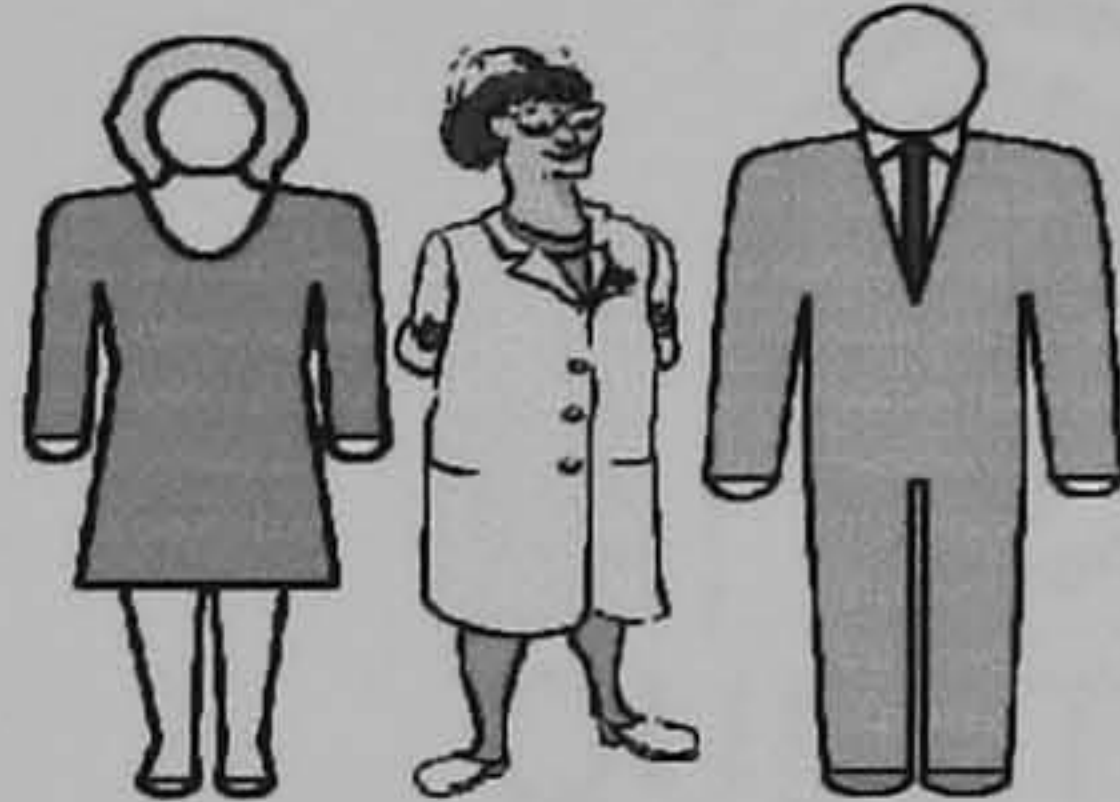


**YOU DO NOT  
NEED TO SAY**

**IF YOU SAY NO, NO ONE WILL BE UPSET OR ANGRY WITH YOU. THE HELP YOU GET NOW WILL STAY THE SAME.**



**NO**



**=**



**OK**

**FAMILY AND STAFF**

4. IF YOU SAY YES

**IF YOU SAY YES I WILL HAVE ONE MEETING WITH YOUR FAMILY OR STAFF.**

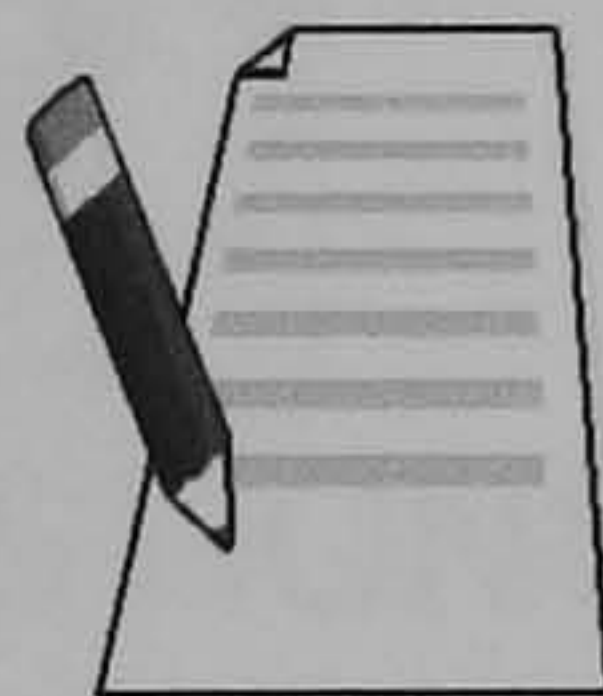


**YES**



**ONE MEETING**

**I WILL ASK THEM TO WRITE DOWN THE ANSWERS TO SOME QUESTIONS**



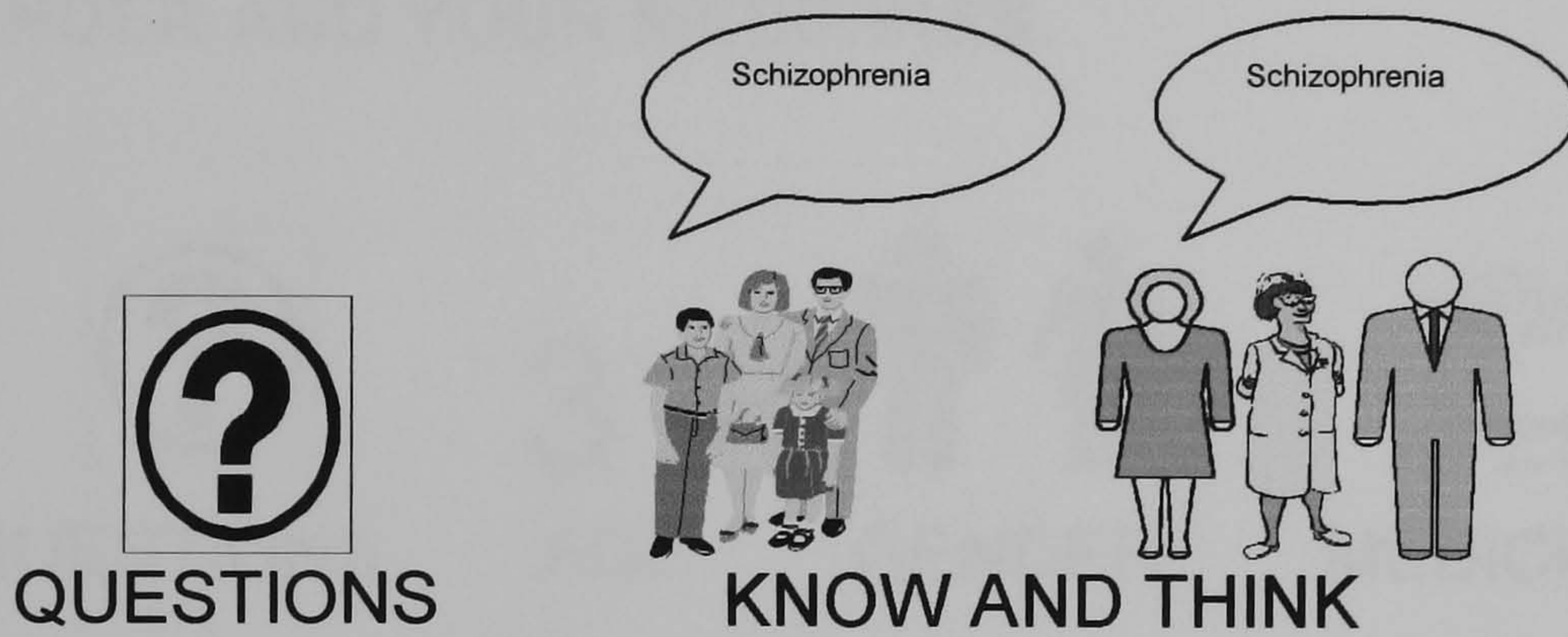
**WRITE DOWN ANSWERS**



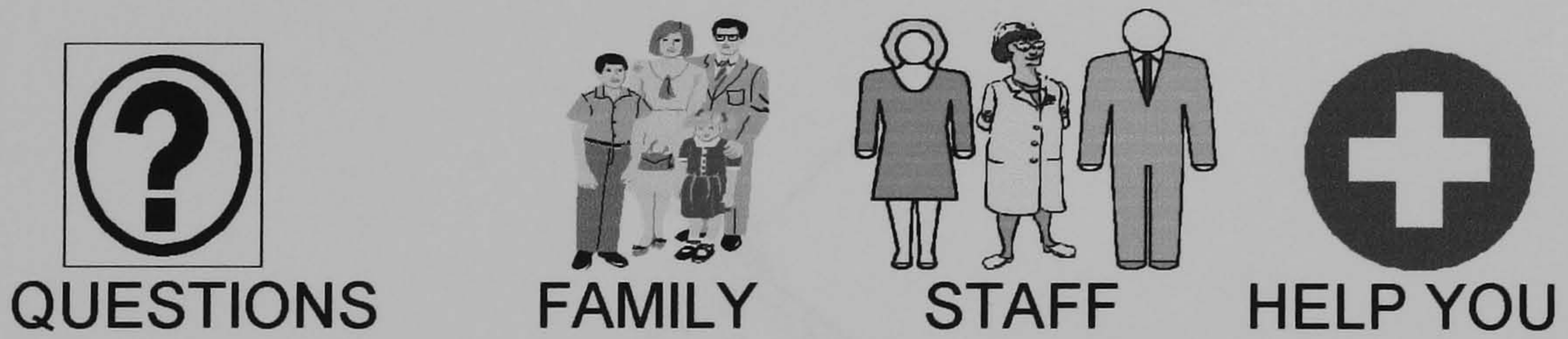
**QUESTIONS**



**THERE ARE QUESTIONS ABOUT WHAT THEY KNOW AND THINK ABOUT SCHIZOPHRENIA.**



**THERE ARE QUESTIONS ABOUT HOW THEY HELP YOU IF YOU ARE UNWELL.**



**THERE ARE SOME QUESTIONS ABOUT HOW THEY FEEL.**



**THERE ARE SOME QUESTIONS ABOUT YOU AND YOUR FAMILY OR STAFF, FOR EXAMPLE, AGE, GENDER AND YOUR MEDICINES.**



**QUESTIONS**

**31**

**AGE**

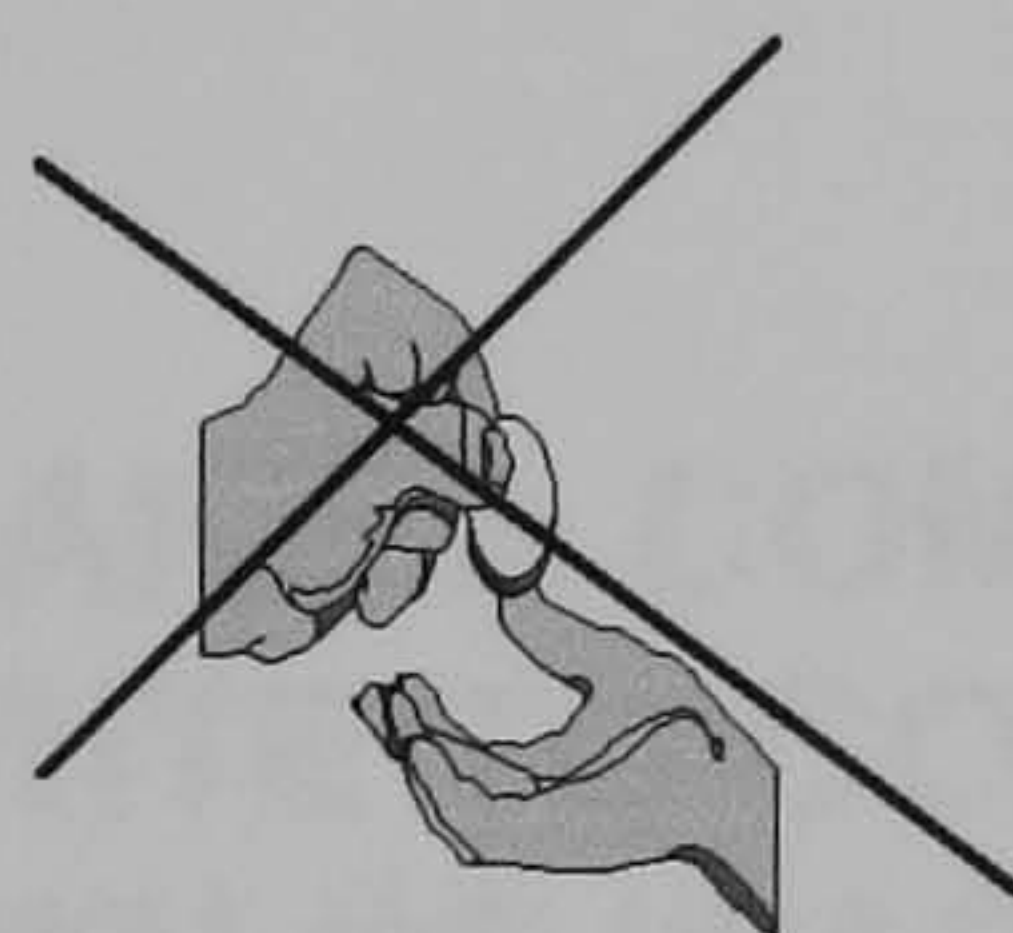


**GENDER**



**MEDICINES**

**NO ONE GETS ANY MONEY FOR WRITING THE ANSWERS TO THE QUESTIONS.**



**NO MONEY**

5. WHAT IF SOMETHING GOES WRONG?

IF YOU ARE UNHAPPY WITH ANY OF THE QUESTIONS YOU CAN TALK TO YOUR FRIENDS, FAMILY, STAFF OR ME (TRACY).



UNHAPPY



QUESTIONS



TALK



FRIENDS



FAMILY



STAFF



TRACY

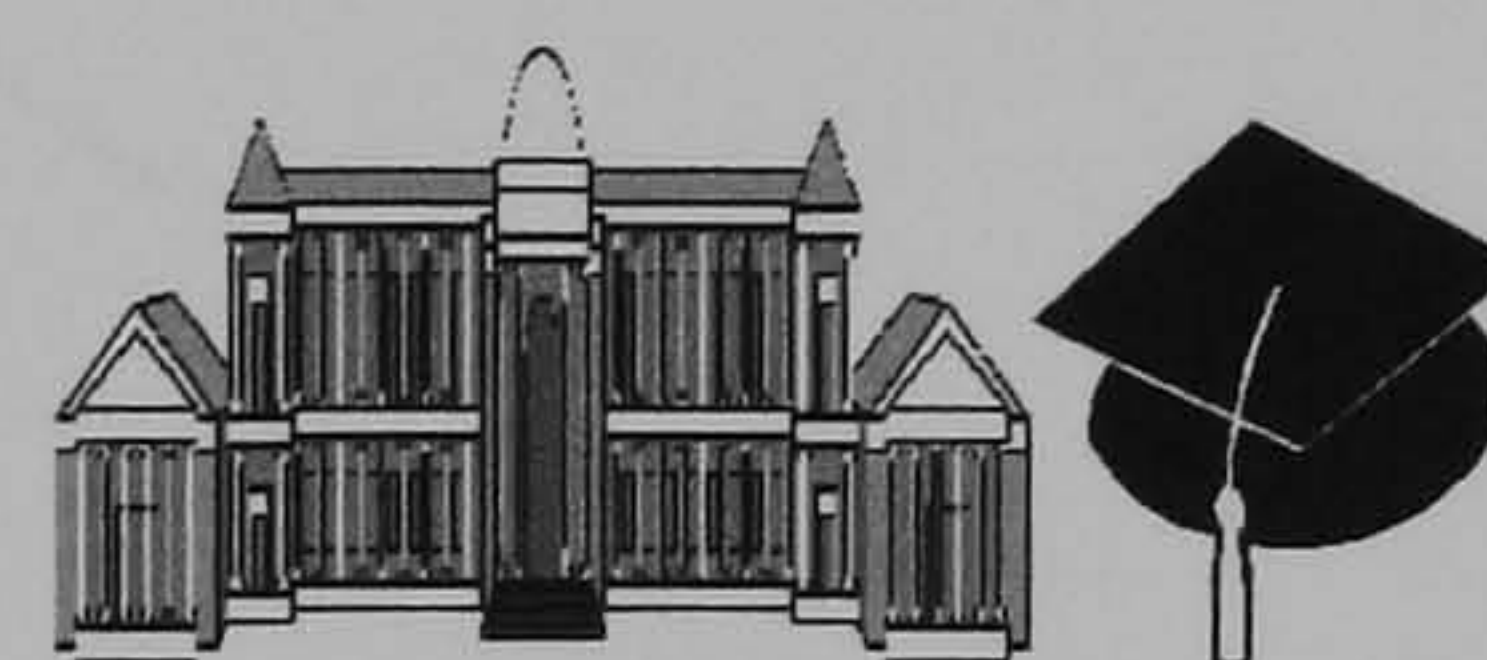
IF YOU WANT TO MAKE A COMPLAINT YOU CAN TELEPHONE OR WRITE TO COVENTRY UNIVERSITY AND THE UNIVERSITY OF WARWICK.



UNHAPPY



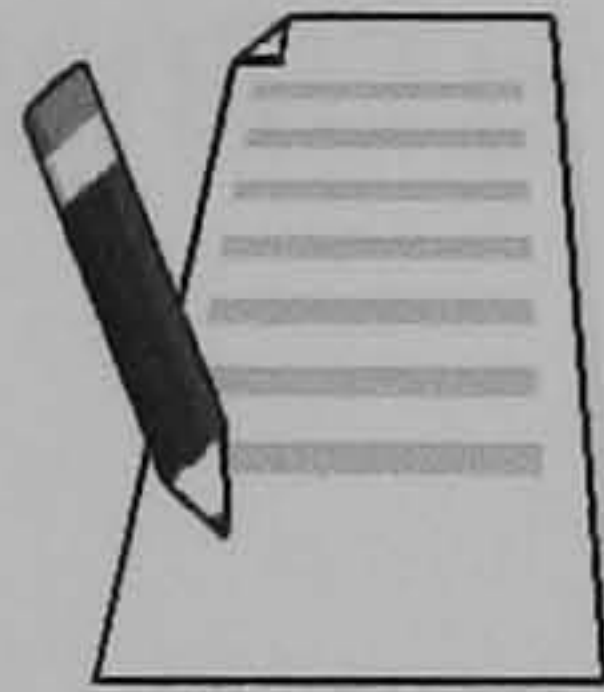
TELEPHONE  
OR WRITE



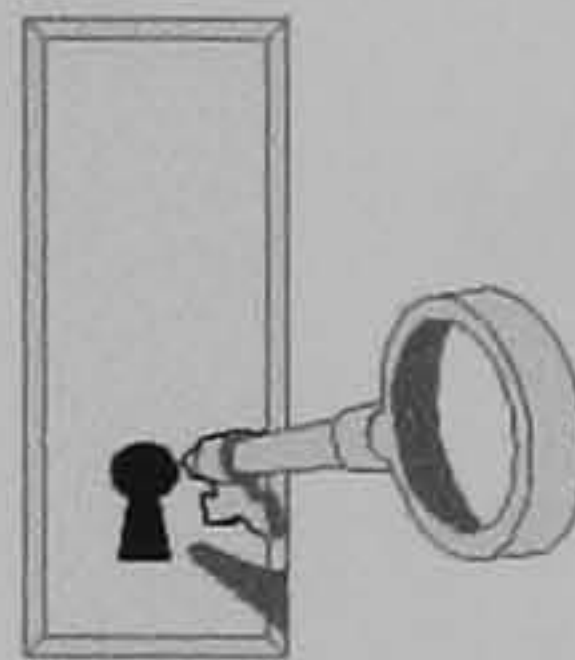
COVENTRY AND  
WARWICK UNIVERSITIES

**6. WILL THE ANSWERS BE KEPT CONFIDENTIAL?**

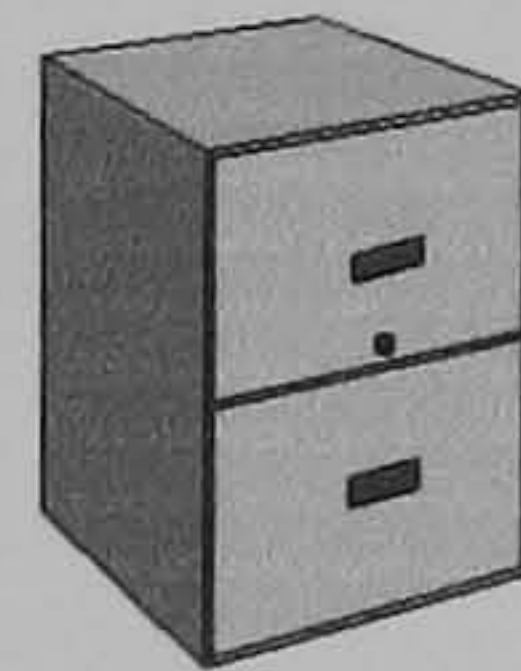
**ALL THE ANSWERS WILL BE KEPT PRIVATE AND CONFIDENTIAL. THEY WILL BE LOCKED IN A FILING CABINET AND ON A COMPUTER.**



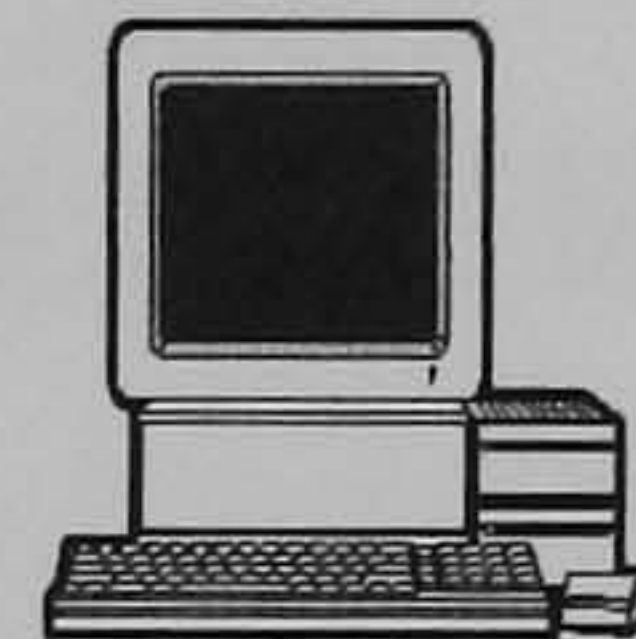
**ANSWERS**



**LOCKED**



**FILING CABINET**



**COMPUTER**

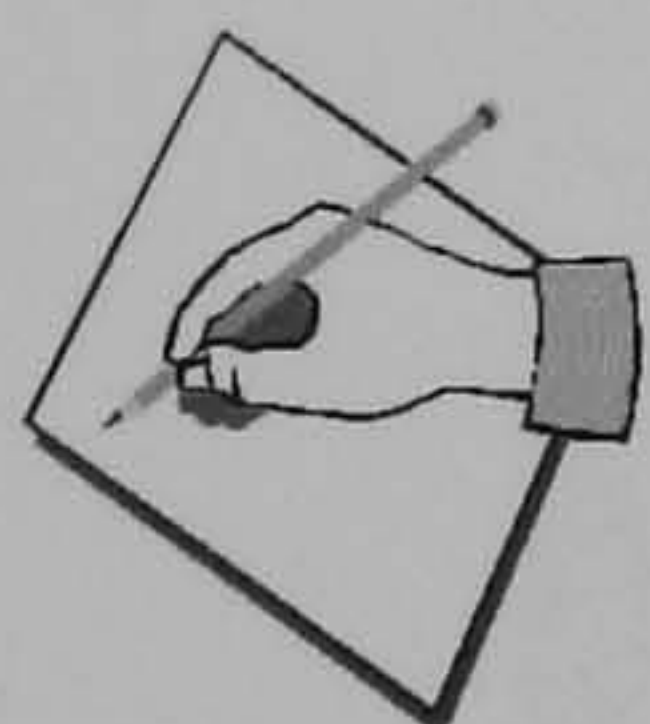
**I DO NOT NEED ANY NAMES OR ADDRESSES.**

~~Fred Smith~~

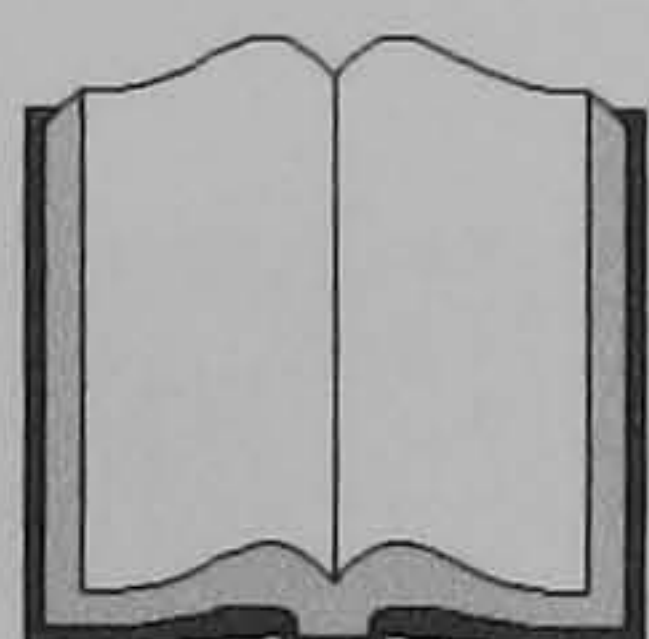
~~10 High Street,  
Bedford.~~

7. WHAT WILL HAPPEN TO THE ANSWERS?

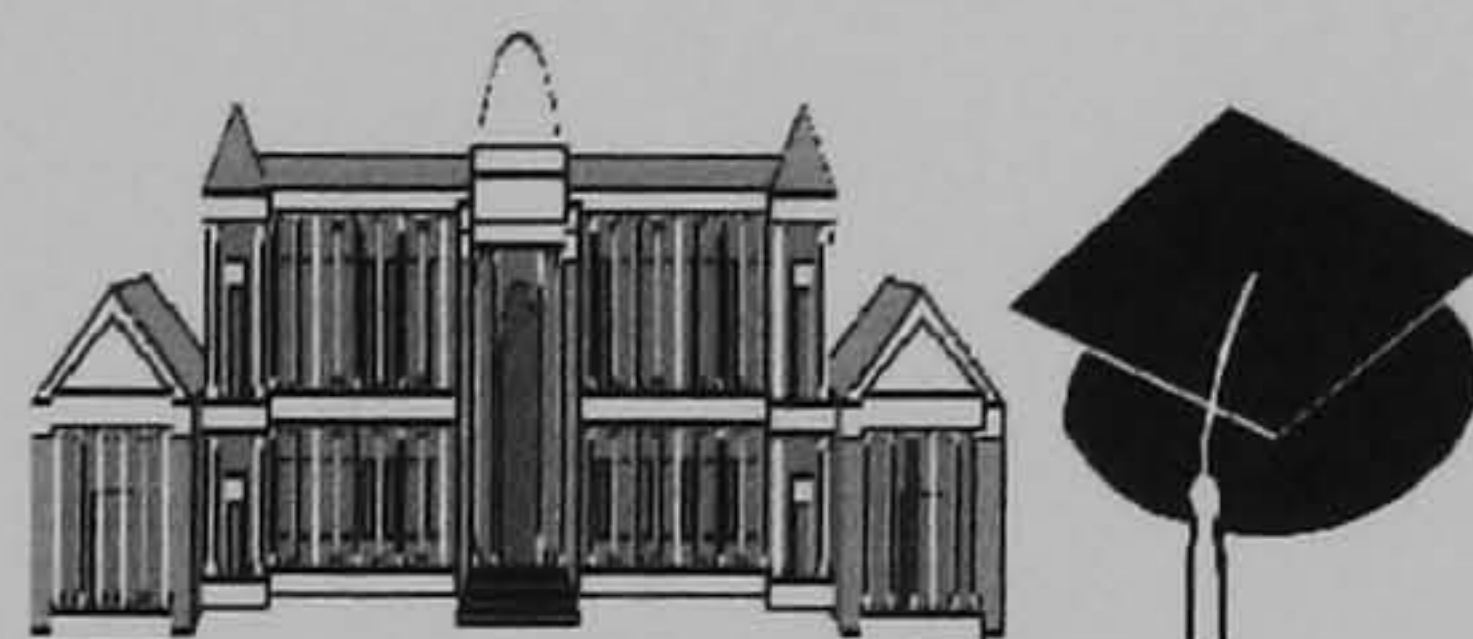
I WILL WRITE A REPORT FOR THE COURSE THAT I AM DOING AT COVENTRY AND WARWICK UNIVERSITIES.



WRITE



REPORT



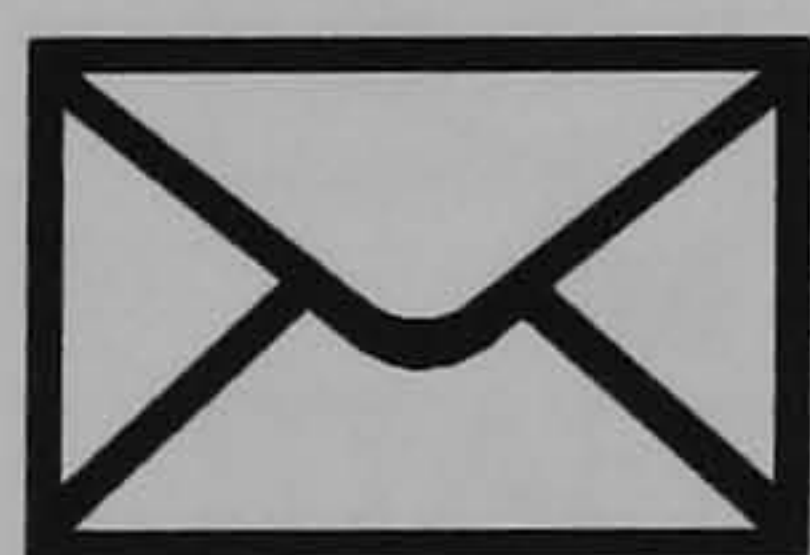
COVENTRY AND  
WARWICK UNIVERSITIES

I WILL FINISH THE REPORT IN MAY NEXT YEAR (2002).

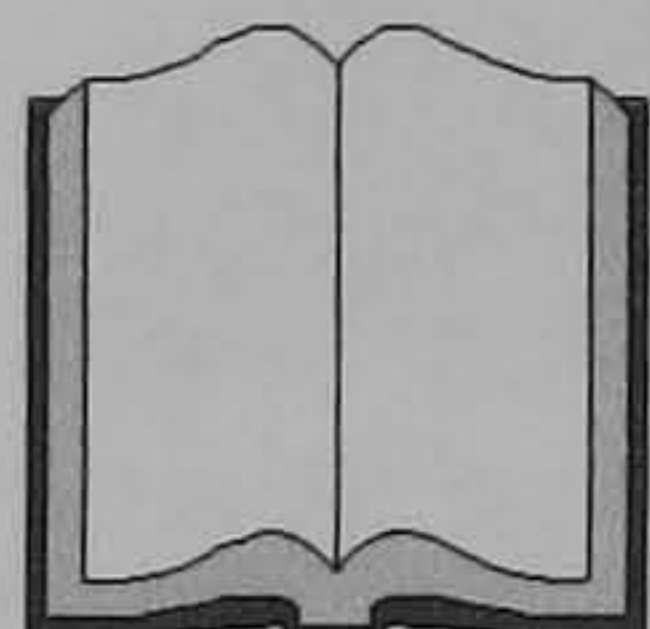
MAY 2002



I WILL ALSO SEND THE REPORT TO A JOURNAL. A JOURNAL LOOKS LIKE A MAGAZINE AND IS READ BY PROFESSIONALS.



SEND



REPORT



PROFESSIONAL

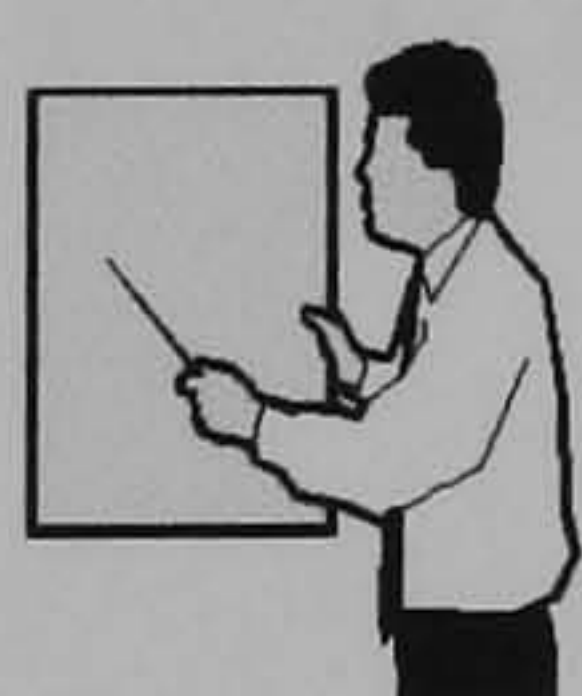
8. WHO IS HELPING ME?

**VAL CROWLEY IS HELPING ME WITH THIS WORK. SHE IS A PSYCHOLOGIST WHO WORKS IN NORTH WARWICKSHIRE.**

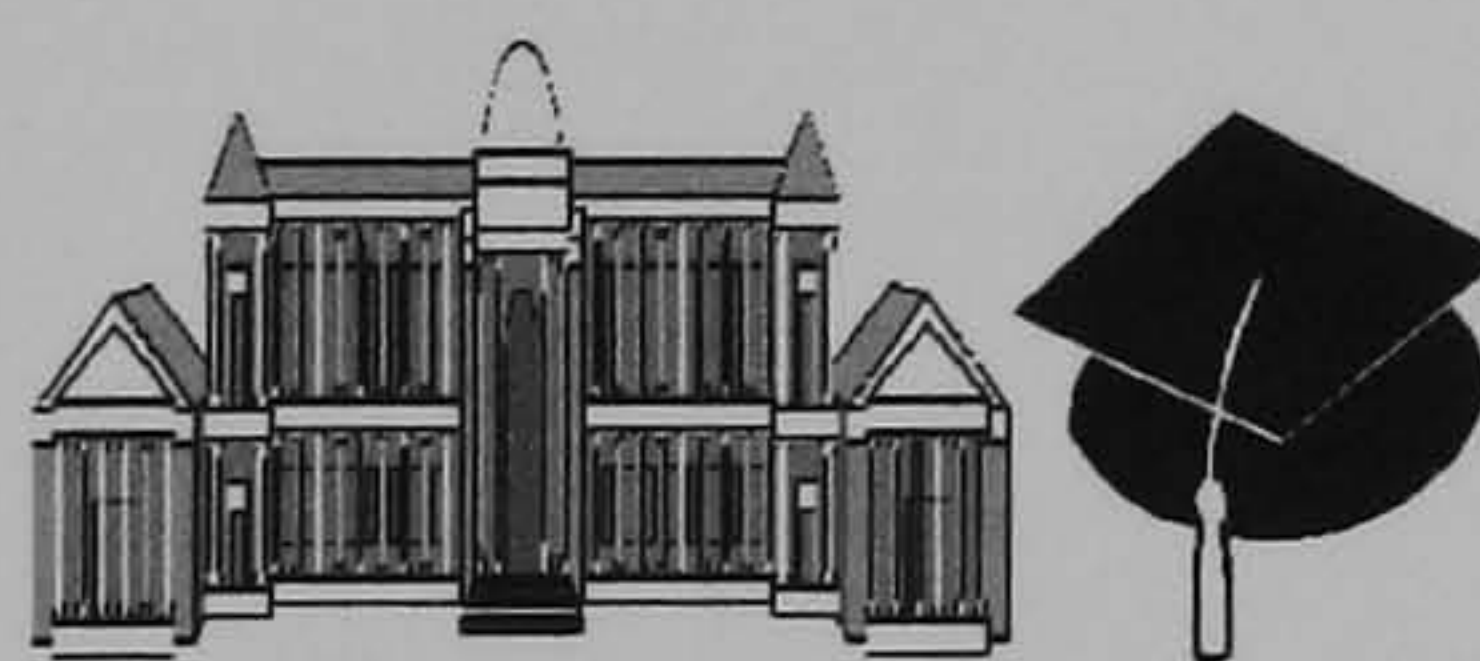


**VAL CROWLEY  
(CLINICAL PSYCHOLOGIST)**

**THE STAFF AT THE UNIVERSITY ARE ALSO HELPING ME.**



**STAFF**

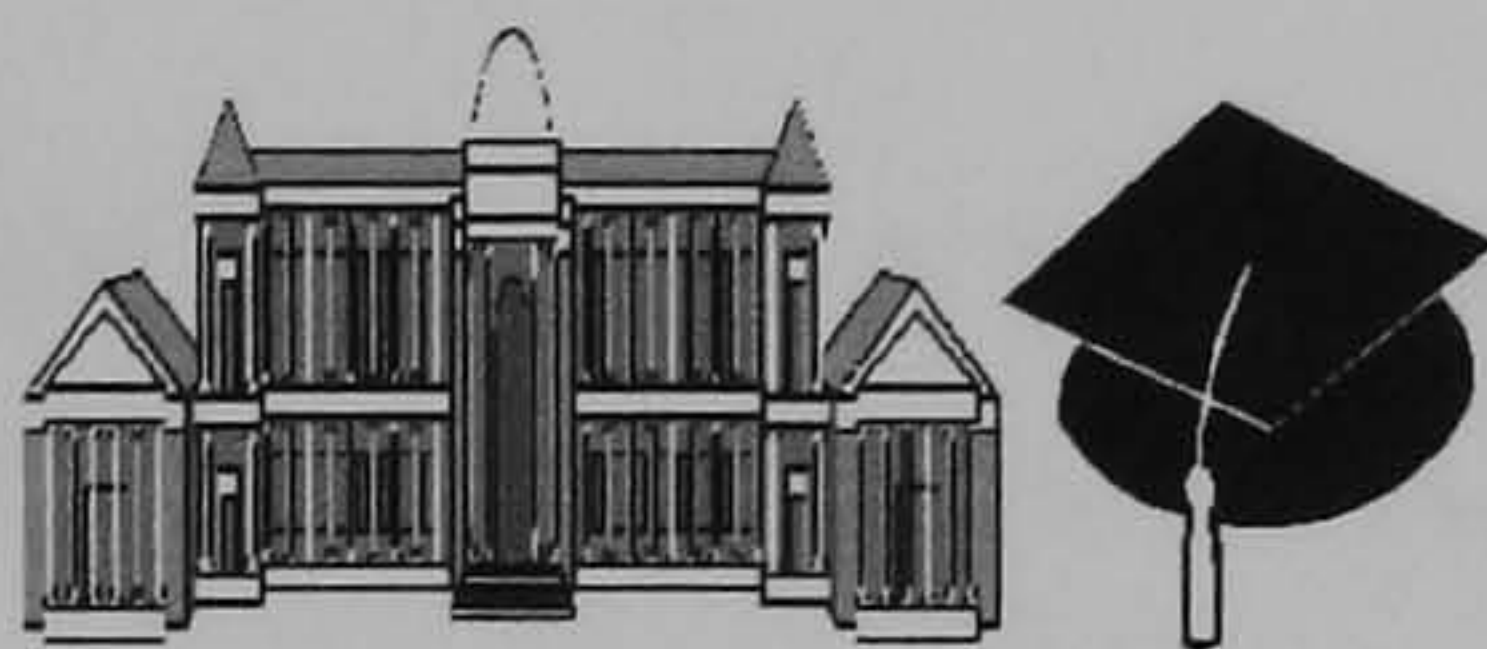


**COVENTRY AND  
WARWICK UNIVERSITIES**

9. **IF YOU HAVE ANY QUESTIONS YOU CAN CONTACT ME AT:**



**TRACY AKRILL  
CLINICAL PSYCHOLOGIST IN TRAINING**



**THE CLINICAL PSYCHOLOGY DEPARTMENT,  
FIFTH FLOOR, B BLOCK,  
SCHOOL OF HEALTH AND SOCIAL SCIENCES,  
COVENTRY UNIVERSITY.  
COVENTRY.**



**(024) 7688 8328.**

**THANK YOU VERY MUCH**

**(Tracy Akrill 22/04/2001 – Information Booklet One)**

**Appendix F**

**North Warwickshire**   
NHS Trust

**PARTICIPANT INFORMATION BOOKLET**

**CARERS OF PEOPLE WITH A LEARNING DISABILITY AND A  
DIAGNOSIS OF SCHIZOPHRENIA.**

N.B. This was presented as an A5 information booklet



**1. Invitation Paragraph**

You are being invited to take part in a research study. Before you decide whether or not to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and professionals if you wish. Please do not hesitate to ask me if there is anything that is not clear or if you would like more information.

**Thank you for reading this booklet.**

**2. What is the purpose of the study?**

There has been limited research with carers of people who have a learning disability and a diagnosis of schizophrenia. Therefore, this research will ask carers about their understanding of schizophrenia, their beliefs about the causes of a number of symptoms and behaviours and it will also ask how carers currently cope with these experiences. The aim of the research is to learn how to support the carers of people with a learning disability and a diagnosis of schizophrenia better in the future. This might involve providing education, coping strategies, ways carers can help the person with schizophrenia and support for the carers themselves.

**3. Why have I been chosen?**

You have been chosen because you currently care for an individual who has a learning disability and a diagnosis of schizophrenia. All other carers in a similar situation in the local area will also be approached and asked if they would consider participating in this research project. This will involve both family carers and professional carers.

**4. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information booklet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the care that the individual that you currently care for receives in anyway.

**5. What will happen to me if I take part?**

The researcher will arrange to meet with you either at your home, the individual's home or at an alternative place, which is convenient for you. The research project will be explained to you and if you agree to participate you will be asked to sign the consent form at that time.

You will then be asked to complete five questionnaires. These questionnaires are relatively straightforward to complete and therefore should not be too 'daunting'. It is anticipated that they will all take about 30 minutes to fill in.

You will only need to meet with the researcher on one occasion in order to complete these questionnaires.

**6. What are the possible disadvantages and risks of taking part?**

It is unlikely that you will experience any distress or discomfort whilst completing the questionnaires. However, you will be able to discuss any concerns that you have with the researcher at any time during this process.

The researcher will also be able to provide information about appropriate services that you will be able to access following the research, if required.

**7. What are the possible benefits of taking part?**

It is hoped that the information that is obtained from this study will help to support carers of individuals with a learning disability and a diagnosis of schizophrenia.

**8. What if something goes wrong?**

If you wish to complain about any aspect of the way that you have been approached or treated during the course of this study, the complaints procedures of Coventry University and The University of Warwick will be available to you.

**9. Will my taking part in this study be kept confidential?**

All the information, which is collected during the course of this study, will be kept **strictly confidential**.

It will not be necessary for you to identify yourself or any other individual on the forms or questionnaires that you complete as part of this study. Therefore, it will not be possible to recognise you from them.

**10. What will happen to the results of the research study?**

The results of this research project will be written up as part of the Doctorate in Clinical Psychology, which the researcher is currently undertaking. This will be completed by May 2002.

It is also expected that a paper based on the results of this research will be submitted to a professional journal after this time. You will be able to receive a brief summary of the results, if required.

You will not be identified in any report or publication.

**11. Who is organising and funding the research?**

This research project is being undertaken as part of the researcher's Doctorate in Clinical Psychology, which is based at Coventry University and The University of Warwick.

I am organising this research project with support from Val Crowley (Clinical Psychologist), Learning Disability Service, Brooklands.

There is no specific funding or additional payments involved in this study.

**12. Who has reviewed the study?**

Staff at Coventry University and The University of Warwick have reviewed this research project. Warwickshire Research Ethics Committee has also reviewed it.

### **Contact for Further Information**

If you require any further information please do not hesitate to contact me at the following address:

Tracy Akrill,  
Clinical Psychologist in Training,  
The Clinical Psychology Department,  
Fifth Floor, B Block,  
School of Health and Social Sciences,  
Coventry University,  
Coventry.

Telephone: (024) 7688 8328.

**THANK YOU VERY MUCH FOR TAKING PART IN THIS STUDY**

You will be given a copy of the information booklet and the signed consent form to keep.

Tracy Akrill 22/04/2001 (Version One)

October 2001

Dear Name of Client and Main Carer (Home Manager/Parents),

We are writing to ask for your help.

Coventry Healthcare NHS Trust is working with the Universities of Coventry and Warwick on a research project, which is focusing on the carers of individuals with a learning disability and a diagnosis of schizophrenia.

The aim of the research is to ask carers about their understanding of schizophrenia and how they cope and support people who have schizophrenia. It is hoped that we will be able to learn more about carers' experiences in order to support carers better in the future, for example, to provide education about schizophrenia, coping strategies, ways carers can help the person with schizophrenia and support for the carers themselves.

We have enclosed some information booklets, one for you and one for your carers. They give details about the research and what your carers will be asked to do. We would be very grateful if you would read the information booklets and consider whether you would be happy to take part in the research. If you need any more information about the research before deciding if you want to take part or not please do not hesitate to contact the researcher, Tracy Akrill, directly on 0121 329 4949 on a Monday, Wednesday or Thursday.

If you are interested in participating and are happy for us to pass on your contact details, then Tracy will contact you to arrange a convenient time and place to meet you and your carers. She will discuss the research with you all in more detail and will then the carers some questions about schizophrenia. If you or your carers do not feel you would like to take part this will in no way affect the services you receive now or in the future.

Please complete the tear off slip below and return it to us in the stamped addressed envelope. It would be really helpful if you could let us know by **20<sup>th</sup> November 2001** whether or not you and your carers would like to take part in the research.

Thank you very much for your time.

Yours sincerely

Dr. G. Marston  
Consultant Psychiatrist

Dr. D. Perry  
Consultant Psychiatrist

**Please tick the appropriate box:**

We would like to take part in the research.

We do not want to take part in the research.

Name (block capitals):.....

If you do want to take part, please give a contact telephone number:.....

**Protocol and Record of Assessment of Client's Capacity to Make a Decision**

**North Warwickshire NHS Trust**

This forms aims to provide a general framework for seeking client consent that can be applied to most situations. Its content reflects the principles for good practice advocated by:

- (i) Mental Health Act (1983)
- (ii) Mental Health Act Code of Practice, 1999; Paragraph 15.10
- (iii) The Government Report "Making Decisions", October 1999

It is for individual practitioners to decide whether to use all or only part of this form on any specific occasion.

The process aims to ensure that:

- (i) There is a functional approach to assessing capacity
- (ii) That assessment of capacity is multidisciplinary, thorough and ongoing
- (iii) Clients are given adequate information in a form that they can understand
- (iv) Clients are supported to think through the consequences of taking different courses of action
- (v) The effect of power in-balance in client/carer and client/professional relationships are minimised
- (vi) If a client is judged as not having capacity, steps are taken to ensure that they have as much information as they want, in a form that they can understand, that their views are taken into account and that they have as much control as possible when practitioners proceed in the "client's best interests".

Client Name: .....	Date of Birth: .....
Address: .....	
.....	
Description of decision to be made:	
.....	
.....	
Names and professionals titles of Assessor(s) (If only one Assessor is involved then just complete for one Assessor throughout the form):	
Assessor 1: .....	Assessor 2: .....
Title: .....	Title: .....
Date of Assessment: .....	Venue of Assessment: .....
Others Present during interactions with client:	
(Names and relationship to the client)	

This form was devised by Brooklands Multidisciplinary Consent Working Party 1998/2000.



Comments and queries should be directed to the Director of Specialist Services or the Customer Services Manager at Brooklands.

**A. Issues for consideration before assessing capacity**

What are the options being presented?

Does the client have a real choice or will the practitioner legally proceed with the proposed course of action even without client consent?

Who should be involved in assessing capacity?

What information needs to be disclosed by who? (complete section B)

What information will not be disclosed and why?

How, where, when should information be given?

What will happen if client is found not to have capacity?

How will "best interest" decisions be made?

Describe here any multidisciplinary liaison/discussion that has taken place to address the above issues and agreed outcomes/action:

Name: ..... Signature: ..... Date: .....

Name: ..... Signature: ..... Date: .....

## **B. Information Given to the Client**

(This section is to record the information to be given to the client)

What is being proposed? (this needs to include what will happen, when and how long it will last – if known)

Who says the client needs it:

Why is it being proposed:

The possible benefits to the client:

The possible risks to the client:

The possible benefits of not proceeding:

The possible risks of not proceeding:

The possible consequences of saying 'no':

What will happen if they say 'yes':

How will the client control what is happening, e.g.: have a break, specify who is there, withdraw consent.....

**C. Meeting(s) with the client**  
**The Manner, Level and Pace of Communication Used**

(Please describe how the information was presented and the client's response)

**Manner** (e.g.: spoken language, gesture, signs, symbols, photographs)

**Level** (e.g.: complex sentences, sentences with two key words, abstract concepts, detailed explanations, short/simple sentences)

**Pace** (e.g.: time for processing what has been said/what to say, number of sessions, length of sessions)

**Please describe how the client responded during the session(s), e.g. any questions they asked, any breakdowns in communication or any other issues arising. Were they attentive, passive, avoided eye contact, distractible.....**

Signature: ..... Date: .....

Signature: ..... Date: .....

## **D. Assessment of Client's Capacity**

Evidence may be drawn from a variety of sources, e.g. previous encounters with the client as well as during a specific "assessment" session – when recording evidence, please indicate the nature of the evidence and when it was obtained. (The questions can be used to assess client's understanding. Delete any that are not used and add others that are; where questions are used, record the client's response verbatim).

**Evidence that the client knows who the person seeking consent is and what their role is**  
(What's my name? What's my job?)

**Evidence that the client understands what the options involve**

(what do I/..... want you to do?)  
(Tell me about option a/b/c)  
(How long will it take?)

**Evidence that the client understands why the options are being presented and by whom,**  
eg:

- (i) in the case of treatment, is there evidence that the client appreciates the disorder and that the doctor is offering treatment,
- (ii) in the case of a home visit, is there evidence that the client understands who is suggesting it and why

**Evidence that the client can apply the options to themselves in real terms**

(What will be good about option a/b/c?)  
(What will be bad about option a/b/c?)

**D Assessment of Client's Capacity (continued)**

**Evidence that the client understands/can reason through the consequences of options a/b/c**  
(What will happen if you do/don't \_\_\_\_\_?)

**Evidence that the client believes that the choice is theirs and is a real one that will be respected** (What will happen if you say 'no'?) (What will happen if you say 'yes'?)

**Evidence that the client is aware of how they can control sessions, withdraw consent etc.**  
(How will you show me when you want a break, want to ask a question.....?)

**Comments:**  
(Please describe questions asked, any gaps in understanding that were explained)

Signature: ..... Date: .....

Signature: ..... Date: .....

**E. Assessor(s)' judgement of whether the client understands and believes enough of the information to make a valid decision**

\* Yes/No/Partially/Don't Know

\* Yes/No/Partially/Don't Know

Assessor 1

Assessor 2

\* delete as appropriate

Comments/Evidence:

Action: (e.g.: steps taken to increase understanding, liaison with MDT re: best interests)

Signature: ..... Date: .....

Signature: ..... Date: .....

**F. Assessor(s)' judgement of whether the client can remember and reason with the information given adequately to weigh up the options**

\* Yes/No/Partially/Don't Know

\* Yes/No/Partially/Don't Know

Assessor 1

Assessor 2

\* delete as appropriate

Comments/Evidence:

Action: (e.g.: liaison with MDT re: best interests)

Signature: ..... Date: .....

Signature: ..... Date: .....

**G. Assessor(s)' judgement of whether the client can assert themselves and express a choice in that situation. Consider issues of over compliance, lack of assertiveness, impact of power imbalance, inexperience of choice/control.**

**\* Yes/No/Partially/Don't Know**

**\* Yes/No/Partially/Don't Know**

**Assessor 1**

**Assessor 2**

**\* delete as appropriate**

**Comments/Evidence:**

**Action: (e.g.: liaison with MDT re: best interests, proceed with compliance but without valid consent)**

**Signature: ..... Date: .....**

**Signature: ..... Date: .....**

**H. Assessor(s)' judgement of whether the client has / has not got capacity to make decision (give valid consent). Take into account:**

- (i) understanding of the information (see Section E)**
- (ii) ability to weigh up the options (See Section F)**
- (iii) the client's ability to assert him/herself to express a real choice in that situation (see Section G)**

**\* Yes/No/Partially/Don't Know**

**\* Yes/No/Partially/Don't Know**

**Assessor 1**

**Assessor 2**

**\* delete as appropriate**

**Comments/Evidence:**

**Action: (e.g.: liaison with MDT re: best interests)**

**Signature: ..... Date: .....**

**Signature: ..... Date: .....**

I. Client's expressed choice and reasons given by client

Comments:

Action: (e.g.: liaison with MDT re best interests)



**J. Outcome of Assessment**

	Assessor One	Assessor Two
Client has not got capacity and is not offered choice	<input type="checkbox"/>	<input type="checkbox"/>
Client has not got capacity and says 'yes'	<input type="checkbox"/>	<input type="checkbox"/>
Client has not got capacity and says 'no'	<input type="checkbox"/>	<input type="checkbox"/>
Client has partial capacity and says 'yes'	<input type="checkbox"/>	<input type="checkbox"/>
Client has partial capacity and says 'no'	<input type="checkbox"/>	<input type="checkbox"/>
Client has capacity and says 'yes'	<input type="checkbox"/>	<input type="checkbox"/>
Client has capacity and says 'no'	<input type="checkbox"/>	<input type="checkbox"/>

Signature: ..... Date: .....

Signature: ..... Date: .....

View of significant Others:.....  
.....

Name & relationship to client:  
.....

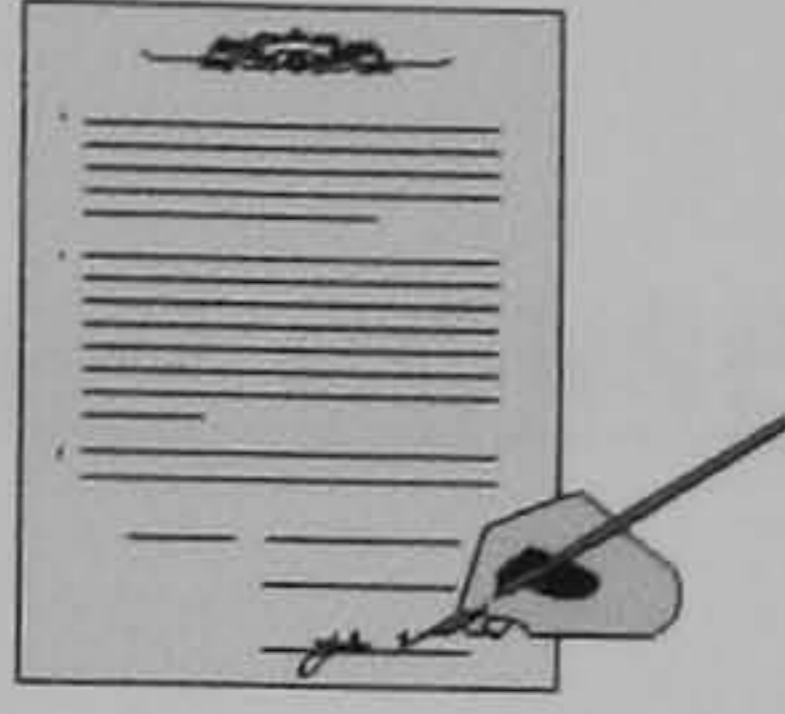
**Action Proposed:**  
(Include how ongoing consent/capacity will be assessed. If client is assessed to not have capacity, specify how client will be given information, control and choice as the situation proceeds in their best interests)

Recommendations for future assessments of capacity:

Signature: ..... Date: .....

Signature: ..... Date: .....

**CONSENT FORM**



**Title of Project:** CARERS OF PEOPLE WHO HAVE A LEARNING DISABILITY AND SCHIZOPHRENIA

**Name of Researcher:** Tracy Akrill


**Please sign the box**


e.g. *Tracy Akrill*

1. I have read and understand the information



booklet that I have been given about this project (Dated 22/04/01 – Version One).

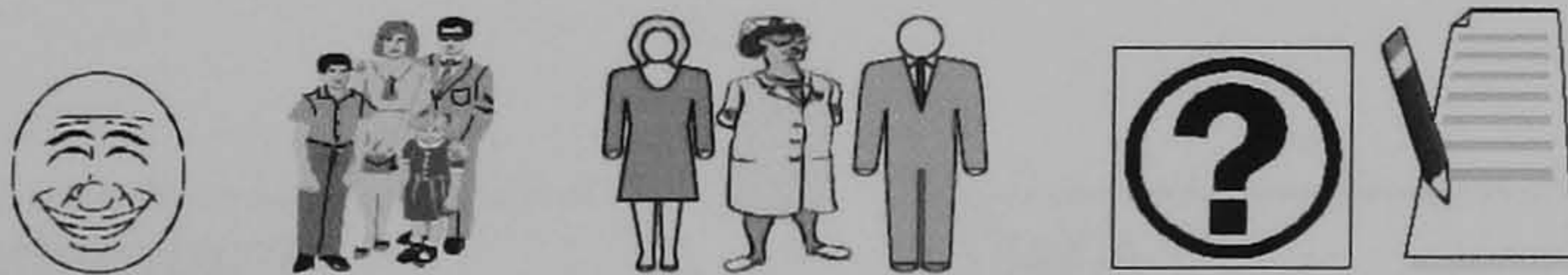
2. I have been able to ask questions .

3. I understand that I can say no at any time without giving a reason. 

4. I understand that if I say no the help I get will stay the same.



5. I am happy for my family or staff to take part in this study. To write down the answers to some questions.



\_\_\_\_\_  
Name of Individual

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**1 copy for individual; 1 copy for researcher; 1 copy to be kept for medical notes**

PARTICIPANT CONSENT FORM

**Title of Project:** CARERS OF PEOPLE WITH A LEARNING DISABILITY  
AND A DIAGNOSIS OF SCHIZOPHRENIA.

**Name of Researcher:** Tracy Akrill

**Please initial box**

- 1. I confirm that I have read and understand the information booklet dated 22/04/2001 (Version One) for the above study and have had the opportunity to ask questions.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that my employment and legal rights will not be affected in any way. I also understand that the care and legal rights of the individual that I currently support will not be affected in any way.
- 3. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 copy for participant; 1 copy for researcher

## APPENDIX K

### The ASchizQ

Thank you very much for agreeing to complete this questionnaire.  
The following instructions will tell you how to complete the questionnaire.  
Thank you for your cooperation.

1. In the box at the top each of the following pages, you will see a brief description. Please read each description very carefully.
2. Then please indicate how frequently the person that you care for has had any of these experiences in the last month (**Question A**).
3. If the person has not had any of these experiences at all, please answer Question A by circling 0 (Not present), and then simply continue to the next page.
4. If the person has had these experiences at least very rarely, please decide what you think is the one main cause of these experiences. There are no right or wrong answers. We are interested in what you think has caused it? While there may be many causes please pick the main one.

Please write one main cause in the blank space provided (**Question B**).

5. Then we want you to answer all of the following questions (**Questions 1 – 7**) about **THE CAUSE** of the experience. The cause is your answer to question B.

For Example:

Question 1: Is **the cause** due to something about the person or something about other people or circumstances?

Totally due to other  
people/circumstances    1    2    3    4    5    6    7    Totally due to  
the person

6. Then simply continue to the next page.

PLEASE CONTINUE OVER THE PAGE

**The person has ideas or beliefs that are unusual or bizarre, e.g.**

- **Thinking that other people want to hurt them,**
- **Believing they are related to someone famous,**
- **Thinking that other people can hear their thoughts or**
- **Believing that something/someone is trying to control them.**

**A. How frequently has the person had any of these experiences during the last month?**  
(Circle one number). If 0 (Not present) please continue to the next page.

0	1	2	3	4	5
Not present	Very rarely	Rarely	Frequently	Very frequently	All of the time

**B. What do you think is the main cause of these experiences? Please write down ONE MAIN CAUSE in the space provided below.** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PLEASE ANSWER ALL OF THE FOLLOWING QUESTIONS ABOUT THE CAUSE OF THESE EXPERIENCES, WHICH YOU HAVE JUST WRITTEN IN THE SPACE ABOVE. CIRCLE ONE NUMBER.**

**1. Is the cause due to something about the person or something about other people or circumstances?**

Totally due to other people/circumstances	1	2	3	4	5	6	7	Totally due to the person
---	---	---	---	---	---	---	---	---------------------------

**2. Is the cause due to something that the person is able to control or something that they are totally unable to control?**

Totally controllable by the person	1	2	3	4	5	6	7	Totally uncontrollable by the person
------------------------------------	---	---	---	---	---	---	---	--------------------------------------

**3. To what extent does the cause involve something unique or unusual about the person's character comparing him/her with other similar people?**

Totally due to the specific character of the person	1	2	3	4	5	6	7	In no way due to the specific character of the person
---	---	---	---	---	---	---	---	---

**4. Is the cause something that affects just the type of situation described in the box above, or does it also influence other areas of this person's life?**

Influences just this situation	1	2	3	4	5	6	7	Influences all situations
--------------------------------	---	---	---	---	---	---	---	---------------------------

**5. In the future, will the cause be present again?**

Will never be present again	1	2	3	4	5	6	7	Will always be present
-----------------------------	---	---	---	---	---	---	---	------------------------

**6. Is the cause due to something about you (the carer) or something about other people or circumstances?**

Totally due to other people/circumstances	1	2	3	4	5	6	7	Totally due to me (the carer)
---	---	---	---	---	---	---	---	-------------------------------

**7. To what extent is the cause controllable by, or uncontrollable by, you (the carer)?**

Totally controllable by me (the carer)	1	2	3	4	5	6	7	Totally uncontrollable by me (the carer)
--	---	---	---	---	---	---	---	--

The person hears, sees, feels, smells or tastes things that are not really there, e.g.

- Hearing a voice or voices talking to them or about them and/or
- Seeing people, faces, objects or shapes that other people do not see.

A. How frequently has the person had any of these experiences during the last month?  
(Circle one number). If 0 (Not present) please continue to the next page.

0                      1                      2                      3                      4                      5  
Not present      Very rarely      Rarely      Frequently      Very frequently      All of the time

B. What do you think is the main cause of these experiences? Please write down ONE MAIN CAUSE in the space provided below. \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PLEASE ANSWER ALL OF THE FOLLOWING QUESTIONS ABOUT THE CAUSE OF THESE EXPERIENCES, WHICH YOU HAVE JUST WRITTEN IN THE SPACE ABOVE. CIRCLE ONE NUMBER.**

1. Is the cause due to something about the person or something about other people or circumstances?

Totally due to other people/circumstances      1      2      3      4      5      6      7      Totally due to the person

2. Is the cause due to something that the person is able to control or something that they are totally unable to control?

Totally controllable by the person      1      2      3      4      5      6      7      Totally uncontrollable by the person

3. To what extent does the cause involve something unique or unusual about the person's character comparing him/her with other similar people?

Totally due to the specific character of the person      1      2      3      4      5      6      7      In no way due to the specific character of the person

4. Is the cause something that affects just the type of situation described in the box above, or does it also influence other areas of this person's life?

Influences just this situation      1      2      3      4      5      6      7      Influences all situations

5. In the future, will the cause be present again?

Will never be present again      1      2      3      4      5      6      7      Will always be present

6. Is the cause due to something about you (the carer) or something about other people or circumstances?

Totally due to other people/circumstances      1      2      3      4      5      6      7      Totally due to me (the carer)

7. To what extent is the cause controllable by, or uncontrollable by, you (the carer)?

Totally controllable by me (the carer)      1      2      3      4      5      6      7      Totally uncontrollable by me (the carer)

**The person's speech seems muddled or confusing, e.g.**

- **Slipping from one topic of conversation to another,**
- **Their answers might not be related to the question asked or**
- **General conversation might be almost impossible to understand.**

**A. How frequently has the person had any of these experiences during the last month?**  
(Circle one number). If 0 (Not present) please continue to the next page.

0	1	2	3	4	5
Not present	Very rarely	Rarely	Frequently	Very frequently	All of the time

**B. What do you think is the main cause of these experiences? Please write down ONE MAIN CAUSE in the space provided below.** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PLEASE ANSWER ALL OF THE FOLLOWING QUESTIONS ABOUT THE CAUSE OF THESE EXPERIENCES, WHICH YOU HAVE JUST WRITTEN IN THE SPACE ABOVE. CIRCLE ONE NUMBER.**

**1. Is the cause due to something about the person or something about other people or circumstances?**

Totally due to other people/circumstances	1	2	3	4	5	6	7	Totally due to the person
---	---	---	---	---	---	---	---	---------------------------

**2. Is the cause due to something that the person is able to control or something that they are totally unable to control?**

Totally controllable by the person	1	2	3	4	5	6	7	Totally uncontrollable by the person
------------------------------------	---	---	---	---	---	---	---	--------------------------------------

**3. To what extent does the cause involve something unique or unusual about the person's character comparing him/her with other similar people?**

Totally due to the specific character of the person	1	2	3	4	5	6	7	In no way due to the specific character of the person
---	---	---	---	---	---	---	---	---

**4. Is the cause something that affects just the type of situation described in the box above, or does it also influence other areas of this person's life?**

Influences just this situation	1	2	3	4	5	6	7	Influences all situations
--------------------------------	---	---	---	---	---	---	---	---------------------------

**5. In the future, will the cause be present again?**

Will never be present again	1	2	3	4	5	6	7	Will always be present
-----------------------------	---	---	---	---	---	---	---	------------------------

**6. Is the cause due to something about you (the carer) or something about other people or circumstances?**

Totally due to other people/circumstances	1	2	3	4	5	6	7	Totally due to me (the carer)
---	---	---	---	---	---	---	---	-------------------------------

**7. To what extent is the cause controllable by, or uncontrollable by, you (the carer)?**

Totally controllable by me (the carer)	1	2	3	4	5	6	7	Totally uncontrollable by me (the carer)
--	---	---	---	---	---	---	---	--

**The person's movements are unusual, e.g.**

- **Being hyperactive for no reason, suddenly taking on odd postures or sitting inactively for long periods of time,**

**AND/OR The person has problems managing their behaviour, e.g.**

- **Dressing unusually, inappropriate sexual behaviour or unpredictable agitation.**

**A. How frequently has the person had any of these experiences during the last month?**  
(Circle one number). If 0 (Not present) please continue to the next page.

0	1	2	3	4	5
Not present	Very rarely	Rarely	Frequently	Very frequently	All of the time

**B. What do you think is the main cause of these experiences? Please write down ONE MAIN CAUSE in the space provided below.** \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PLEASE ANSWER ALL OF THE FOLLOWING QUESTIONS ABOUT THE CAUSE OF THESE EXPERIENCES, WHICH YOU HAVE JUST WRITTEN IN THE SPACE ABOVE. CIRCLE ONE NUMBER.**

**1. Is the cause due to something about the person or something about other people or circumstances?**

Totally due to other people/circumstances	1	2	3	4	5	6	7	Totally due to the person
---	---	---	---	---	---	---	---	---------------------------

**2. Is the cause due to something that the person is able to control or something that they are totally unable to control?**

Totally controllable by the person	1	2	3	4	5	6	7	Totally uncontrollable by the person
------------------------------------	---	---	---	---	---	---	---	--------------------------------------

**3. To what extent does the cause involve something unique or unusual about the person's character comparing him/her with other similar people?**

Totally due to the specific character of the person	1	2	3	4	5	6	7	In no way due to the specific character of the person
---	---	---	---	---	---	---	---	---

**4. Is the cause something that affects just the type of situation described in the box above, or does it also influence other areas of this person's life?**

Influences just this situation	1	2	3	4	5	6	7	Influences all situations
--------------------------------	---	---	---	---	---	---	---	---------------------------

**5. In the future, will the cause be present again?**

Will never be present again	1	2	3	4	5	6	7	Will always be present
-----------------------------	---	---	---	---	---	---	---	------------------------

**6. Is the cause due to something about you (the carer) or something about other people or circumstances?**

Totally due to other people/circumstances	1	2	3	4	5	6	7	Totally due to me (the carer)
---	---	---	---	---	---	---	---	-------------------------------

**7. To what extent is the cause controllable by, or uncontrollable by, you (the carer)?**

Totally controllable by me (the carer)	1	2	3	4	5	6	7	Totally uncontrollable by me (the carer)
--	---	---	---	---	---	---	---	--



The person seem as if they have lost some of their emotions in some way, e.g.  
 • Things don't seem funny anymore,  
 AND/OR the person seems to have lost interest and enjoyment in activities or interests, e.g.  
 • They might find it difficult to get up in the mornings.  
 AND/OR the person doesn't say very much and what they say doesn't make much sense.

A. How frequently has the person had any of these experiences during the last month?  
 (Circle one number). If 0 (Not present) please continue to the next page.

0	1	2	3	4	5
Not present	Very rarely	Rarely	Frequently	Very frequently	All of the time

B. What do you think is the main cause of these experiences? Please write down ONE MAIN CAUSE in the space provided below. \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**PLEASE ANSWER ALL OF THE FOLLOWING QUESTIONS ABOUT THE CAUSE OF THESE EXPERIENCES, WHICH YOU HAVE JUST WRITTEN IN THE SPACE ABOVE. CIRCLE ONE NUMBER.**

1. Is the cause due to something about the person or something about other people or circumstances?

Totally due to other people/circumstances	1	2	3	4	5	6	7	Totally due to the person
---	---	---	---	---	---	---	---	---------------------------

2. Is the cause due to something that the person is able to control or something that they are totally unable to control?

Totally controllable by the person	1	2	3	4	5	6	7	Totally uncontrollable by the person
------------------------------------	---	---	---	---	---	---	---	--------------------------------------

3. To what extent does the cause involve something unique or unusual about the person's character comparing him/her with other similar people?

Totally due to the specific character of the person	1	2	3	4	5	6	7	In no way due to the specific character of the person
---	---	---	---	---	---	---	---	---

4. Is the cause something that affects just the type of situation described in the box above, or does it also influence other areas of this person's life?

Influences just this situation	1	2	3	4	5	6	7	Influences all situations
--------------------------------	---	---	---	---	---	---	---	---------------------------

5. In the future, will the cause be present again?

Will never be present again	1	2	3	4	5	6	7	Will always be present
-----------------------------	---	---	---	---	---	---	---	------------------------

6. Is the cause due to something about you (the carer) or something about other people or circumstances

Totally due to other people/circumstances	1	2	3	4	5	6	7	Totally due to me (the carer)
---	---	---	---	---	---	---	---	-------------------------------

7. To what extent is the cause controllable by, or uncontrollable by, you (the carer)?

Totally controllable by me (the carer)	1	2	3	4	5	6	7	Totally uncontrollable by me (the carer)
--	---	---	---	---	---	---	---	--

**APPENDIX L**  
**INFORMATION ABOUT YOU THE PROFESSIONAL CARER**

1. Age: \_\_\_\_\_ 2. Gender: Male  Female

3. Marital Status:  
 Married   
 Single   
 Divorced   
 Widowed   
 Separated   
 Co-habiting

4. Ethnic Origin:  
 White   
 Black   
 Asian   
 Other (please specify)  
 \_\_\_\_\_

5. Please describe your relationship to the person with a learning disability and a diagnosis of schizophrenia (e.g. professional carer – care assistant, support worker, manager etc) \_\_\_\_\_  
 \_\_\_\_\_

6. How long have you worked with people with learning disabilities?  
 \_\_\_\_\_ (years/months)

7. How long have you been working with this person?  
 0 – 6 months  6 months – 1 year   
 1 – 2 years  2 – 3 years   
 3 – 4 years  4 – 5 years   
 5 – 6 years  6 – 7 years   
 Other (please specify) \_\_\_\_\_  
 \_\_\_\_\_

8. On average how many hours of direct contact do you have with this person during an average week?  
 0-9 hours  10-19 hours   
 20-29 hours  30-39 hours   
 40-49 hours  50 hours or more (please specify)  
 \_\_\_\_\_ (hours)

9. Have you ever received any support, information or training about schizophrenia or mental health issues? YES  NO

If yes, please provide some brief details: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**THANK YOU FOR COMPLETING THIS QUESTIONNAIRE**

**APPENDIX M**  
**INFORMATION ABOUT THE PERSON YOU CARE FOR**

1. Age: \_\_\_\_\_ 2. Gender: Male  Female

3. Marital Status:  
 Single   
 Married   
 Divorced   
 Widowed   
 Separated   
 Co-habiting

4. Ethnic Origin:  
 White   
 Black   
 Asian   
 Other (please specify) \_\_\_\_\_

5. What type of accommodation does this person live in?  
 Own tenancy  Group home  Family home   
 Other (please specify) \_\_\_\_\_

6. How many other people does this person live with? \_\_\_\_\_

7. At what age did this person receive a diagnosis of schizophrenia?  
 0-9 years  40-49 years   
 10-19 years  Don't Know   
 20-29 years  Other (please specify) \_\_\_\_\_  
 30-39 years

8. What medication does this person currently take?

Name of medication	Dose	Frequency

**PLEASE TURN OVER**

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IN  
ORIGINAL**

**The Knowledge Questionnaire**

**Please read the following questions carefully and answer all the questions on the following pages by placing a tick in the appropriate box(es). Please tick one answer only unless the question states there is more than one answer. If you have any additional comments please write them in the spaces provided below each question.**

1. Who can become schizophrenic?

1)	Anyone	
2)	Men Only	
3)	People with personality disorders	
4)	Criminals	
5)	Don't know	

Any other comments:

2. The usual age when the illness first attacks is:

1)	Anytime	
2)	Middle age	
3)	In early twenties	
4)	Childhood	
5)	Don't know	

Any other comments:

3. The chance of developing schizophrenia is:

1)	1 in 1000	
2)	1 in 500	
3)	1 in 100	
4)	1 in 200	
5)	Don't know	

Any other comments:

4. If you are a child of someone who has schizophrenia the chances of you also having schizophrenia are:

1)	The same as anyone else	
2)	Higher than anyone else	
3)	Lower than anyone else	
4)	A 99% possibility that you will also have schizophrenia	
5)	Don't know	

Any other comments:

**PLEASE CONTINUE OVER THE PAGE**

5. An attack of schizophrenia may be triggered by:

1)	A knock on the head	
2)	Difficulties at birth	
3)	Physical illness	
4)	Stress	
5)	Don't know	

Any other comments:

6. Which of the following is the most common in schizophrenia?

1)	To have just one attack and recover completely	
2)	To have several attacks but with periods when you feel better in between	
3)	To be permanently ill with no periods of recovery whatever	
4)	To have one attack but not completely recover to what you were before	
5)	Don't know	

Any other comments:

7. Which of the following do you believe are common symptoms of schizophrenia?  
(There is more than one answer)

1)	Hearing voices	
2)	Lack of energy	
3)	Incontinence	
4)	Delusions	
5)	Headaches	
6)	Irritability	
7)	Loss of appetite	
8)	Lack of affection	
9)	Sleep problems	
10)	Over activity	
11)	Withdrawal	
12)	Don't know	

Any other comments:

**PLEASE CONTINUE OVER THE PAGE**

8. Which of the following are negative symptoms of schizophrenia?

(There is more than one answer)

1)	Hearing voices	
2)	Withdrawal	
3)	Lack of affection	
4)	Lack of energy	
5)	Thought disorder	
6)	Delusions	
7)	Irritability	
8)	Don't know	

Any other comments:

9. A positive symptom of schizophrenia is?

1)	A symptom that is definitely due to schizophrenia and not due to anything else	
2)	A symptom that is used to diagnose schizophrenia	
3)	When something is added to a persons normal behaviour	
4)	When there is a loss from the persons normal behaviour	
5)	Don't know	

Any other comments:

10. When schizophrenic symptoms reappear and get much worse this is called?

1)	Relapse	
2)	Omission	
3)	Remission	
4)	Prolapse	
5)	Don't know	

Any other comments:

11. When a person with schizophrenia is admitted to hospital under 'section' this means?

1)	Voluntary admission	
2)	Compulsory admission	
3)	Admission with the patients consent	
4)	Admission by the police	
5)	Don't know	

Any other comments:

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12. The average length of stay in hospital for a first attack of schizophrenia is:

1)	3-6 weeks	
2)	6 months	
3)	12 weeks	
4)	One year	
5)	Don't know	

Any other comments:

13. Medication can help reduce (remove symptoms) in what % of patients?

1)	25% (quarter)	
2)	75% (three quarters)	
3)	50% (half)	
4)	100% (all)	
5)	Don't know	

Any other comments:

14. The main medication to remove schizophrenic symptoms are:

1)	Antihistamines	
2)	Narcotics	
3)	Neuroleptics	
4)	Tranquillisers	
5)	Don't know	

Any other comments:

15. If a schizophrenic patient is taking his medication the risk of getting a second attack of schizophrenia within one year is reduced from 75% to:

1)	70%	
2)	50%	
3)	10%	
4)	30%	
5)	Don't know	

Any other comments:

16. Rehabilitation is the word for:

1)	Giving medication	
2)	Helping the patient to settle back to a normal life out of hospital	
3)	Helping the patient to find accommodation	
4)	Hospital treatment	
5)	Don't know	

Any other comments:

**PLEASE CONTINUE OVER THE PAGE**



17. Medication is more effective with:

1)	Positive symptoms	
2)	Negative symptoms only	
3)	All symptoms equally	
4)	Mainly negative symptoms	
5)	Don't know	

Any other comments:

18. Which of the following are often associated with the onset of schizophrenia? (There is more than one answer)

1)	Too much stress	
2)	Poor diet	
3)	Inability to get angry and express your feelings directly	
4)	Runs in the family	
5)	Biological problems, body chemicals	
6)	Personality 'type' – just the kind of person	
7)	A split in the personality	
8)	Family problems while he/she was a child	
9)	An upsetting experience, loss of an important person, e.g. death, divorce etc.	
10)	Don't know	

Any other comments:

19. To help themselves the family member/carers should: (There is more than one answer)

1)	Leave the person totally alone	
2)	Talk about their difficulties with friends or colleagues	
3)	Try and forget about the difficulties and problems they have to face	
4)	Get out doing things and/or seeing friends	
5)	Help the patient as much as possible but make sure that they still keep their own interests and hobbies	
6)	Put all their effort and time into helping the patient recover	
7)	Ignore the patient and try to get on with their own lives	
8)	Don't know	

Any other comments:

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20. To help the person recover from schizophrenia the family member/carers should try to: (There is more than one answer)

1)	Leave the person alone	
2)	Try to get him to do things for himself	
3)	Do as much for the person as possible	
4)	Encourage him to go out and mix with people	
5)	Let the patient do what he wants to do	
6)	Not burden the patient with household tasks	
7)	Ensure that he takes his medication	
8)	Don't know	

Any other comments:

21. Which of the following are unhelpful to a person with schizophrenia:  
(There is more than one answer)

1)	Too much pressure on the person	
2)	Nagging by the family member/carers	
3)	Sitting around all day	
4)	Stopping taking medication	
5)	Giving the person responsibility	
6)	Treating the person like an adult	
7)	Don't know	

Any other comments:

22. If you notice side effects of the medication that the person you care for is taking you should:

1)	Wait and see if the side effects go away	
2)	Ask the doctors advice	
3)	Come off the medication altogether	
4)	Take a lower dose of the medication than that prescribed by the doctor	
5)	Don't know	

Any other comments:

23. The best environment for a person suffering from schizophrenia is where:

1)	The person can do what he likes	
2)	The person spends most of his time with another family or household member or carer	
3)	The person is forced to go out and get a job	
4)	The person is encouraged to take up things he used to do	
5)	The family/carer takes care of all the persons needs and protects the person from any stress	
6)	Don't know	

Any other comments:

## APPENDIX O

### CARER COPING STYLE QUESTIONNAIRE (CCSQ)

The following questions are about your experiences in caring for someone with schizophrenia. Please circle the appropriate number to show how much you agree or disagree with each statement

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1. I think s/he sometimes says things or does things on purpose just to annoy me	1	2	3	4	5
2. I sometimes go along with his/her funny ideas or behaviour, just to keep the peace.	1	2	3	4	5
3. I often reassure him/her that everything is going to be OK.	1	2	3	4	5
4. I get terribly upset when I think about his/her illness (schizophrenia).	1	2	3	4	5
5. I often try to involve him/her in things I'm doing, even if s/he is not really interested in them.	1	2	3	4	5
6. I don't like him/her to be on his/her own.	1	2	3	4	5
7. I don't try to cheer him/her up anymore as I've found that nothing I say makes any difference.	1	2	3	4	5
8. If s/he says odd or strange things, I try not to take too much notice.	1	2	3	4	5
9. On occasion, I laugh at him/her when s/he says or does silly things.	1	2	3	4	5
10. I sometimes do things s/he asks me to do even though I know they are ridiculous.	1	2	3	4	5
11. When s/he worries about things I remind him/her that we care about him/her.	1	2	3	4	5
12. I don't know how to cope when s/he gets upset.	1	2	3	4	5
13. I often find myself encouraging him/her to do things.	1	2	3	4	5
14. I try to do most things for him/her.	1	2	3	4	5
15. Despite everything, I really enjoy his/her company.	1	2	3	4	5
16. At times I find myself getting so angry with him/her.	1	2	3	4	5
17. If s/he thinks people are watching him/her or talking about him/her I sometimes pretend to check on this in order to make him/her feel better.	1	2	3	4	5
18. When s/he gets upset I do my best to reassure him/her.	1	2	3	4	5
19. S/he knows that I worry terribly about him/her.	1	2	3	4	5

PLEASE CONTINUE OVER THE PAGE

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
20. I try to take his/her mind off morbid thoughts.	1	2	3	4	5
21. I used to try and distract him/her when s/he was behaving strangely, but now I've realised that there isn't any point in doing this.	1	2	3	4	5
22. I've found that if s/he gets upset, it's best to leave him/her to sort it out him/herself.	1	2	3	4	5
23. There are many times when it's nice for us to be together.	1	2	3	4	5
24. We often argue over little things.	1	2	3	4	5
25. I can't see anything wrong in humouring his/her funny ideas now and then.	1	2	3	4	5
26. When s/he gets upset I try to calm him/her down.	1	2	3	4	5
27. When s/he gets upset I feel so helpless.	1	2	3	4	5
28. Sometimes I make up little jobs that don't really need doing so that it will occupy him/her	1	2	3	4	5
29. I'm always asking him/her if s/he is OK.	1	2	3	4	5
30. Basically, with regard to his/her illness (schizophrenia), I've just given up.	1	2	3	4	5
31. If s/he wants to spend large amounts of time on his/her own, I let him/her, I don't interfere.	1	2	3	4	5
32. S/he can be so unreasonable and stubborn at times.	1	2	3	4	5
33. If s/he says strange things I sometimes agree with him/her, even though I know they're not really true.	1	2	3	4	5
34. When s/he gets worried or upset I try to stay calm and remind him/her that everything will be all right.	1	2	3	4	5
35. I do everything I can to help him/her, but I feel so powerless.	1	2	3	4	5
36. I try to help him/her work out what's real and what's just in his/her imagination.	1	2	3	4	5
37. I feel that I have to protect him/her from the outside world.	1	2	3	4	5
38. I used to try and involve him/her in things, but I don't bother any more, as it doesn't help.	1	2	3	4	5

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	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
39. Frankly, I've just got used to him/her being the way s/he is and I don't really notice it anymore.	1	2	3	4	5
40. I enjoy spending time with him/her.	1	2	3	4	5
41. It's only when I really lose my temper that s/he takes any notice of what I'm saying.	1	2	3	4	5
42. I sometimes agree with his/her 'funny ideas' in order not to upset him/her.	1	2	3	4	5
43. When s/he expresses upsetting or worrying ideas I remind him/her that we are here to help him/her.	1	2	3	4	5
44. I sometimes think that his/her life just isn't worth living.	1	2	3	4	5
45. I try to draw him/her into conversations.	1	2	3	4	5
46. I've given up making suggestions to him/her, as nothing makes any difference.	1	2	3	4	5
47. I try to stay out of his/her way as much as possible.	1	2	3	4	5
48. We get on well together.	1	2	3	4	5
49. I must admit that at times I find myself shouting at him/her.	1	2	3	4	5
50. On occasion I go along with the strange things s/he says or does, in order to reassure him/her.	1	2	3	4	5
51. I often tell him/her that nothing bad can happen when s/he's with us.	1	2	3	4	5
52. I suggest things to him/her that s/he might enjoy.	1	2	3	4	5
53. I used to try talking him/her out of his/her problems, but now I've realised that it doesn't help.	1	2	3	4	5
54. I avoid saying certain things so s/he won't get upset.	1	2	3	4	5
55. We do as many things together as possible.	1	2	3	4	5
56. I find myself nagging him/her to do more around the house.	1	2	3	4	5
57. I sometimes pretend to agree with the things s/he says, even though I know it's just his/her imagination.	1	2	3	4	5

PLEASE CONTINUE OVER THE PAGE

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
58. I keep reminding him/her that s/he is a good person and nobody wants to harm him/her.	1	2	3	4	5
59. I remind him/her that if s/he wants to talk to someone, I'm around.	1	2	3	4	5
60. When I think about his/her illness (schizophrenia), I realise now that s/he'll never get any better.	1	2	3	4	5
61. When I can see that s/he's troubled I know it's best to leave him/her alone.	1	2	3	4	5
62. I try to spend as much time with him/her as possible.	1	2	3	4	5
63. When s/he says things that don't make sense, I tell him/her s/he's talking nonsense.	1	2	3	4	5
64. It's best to play along with his/her ideas, as disagreeing just upsets him/her.	1	2	3	4	5
65. I try to reassure him/her that s/he can rely on our support.	1	2	3	4	5
66. When I think about him/her I get very upset.	1	2	3	4	5
67. I try to distract him/her from the 'voices'.	1	2	3	4	5
68. I realise now that s/he is always going to be like this.	1	2	3	4	5
69. If s/he behaves in an odd or strange way, I just accept it as part of his/her illness (schizophrenia).	1	2	3	4	5
70. There are lots of good things about him/her, even though s/he has his/her problems.	1	2	3	4	5
71. I tell him/her that s/he must do more for him/herself if s/he wants to get better.	1	2	3	4	5
72. In order to reassure him/her I sometimes pretend that I can hear the 'voices' too.	1	2	3	4	5
73. I encourage him/her to do more for him/herself.	1	2	3	4	5
74. I think that pressurising him/her might make him/her really ill.	1	2	3	4	5
75. I think it's best to leave it all to the doctors.	1	2	3	4	5
76. It's best to leave him/her alone if s/he hears voices and to get on with things that I need to do.	1	2	3	4	5

THANK YOU VERY MUCH FOR COMPLETING THIS QUESTIONNAIRE

## Appendix P

### MODIFICATIONS MADE TO THE CARER COPING STYLE QUESTIONNAIRE

CCSQ ORIGINAL	CCSQ MODIFIED VERSION
CRITICISM/COERCION (ORIGINAL)	CRITICISM/COERCION (MODIFIED)
At times I find myself getting so angry with him/her.	At times I find myself getting so angry with him/her.
On occasion, I laugh at him/her when s/he says or does silly things.	On occasion, I laugh at him/her when s/he says or does silly things.
I think s/he sometimes says things on purpose just to annoy me.	I think s/he sometimes says things or does things on purpose just to annoy me.
We often argue over little things.	We often argue over little things.
S/he can be so unreasonable and stubborn at times.	S/he can be so unreasonable and stubborn at times.
It's only when I really lose my temper that s/he takes any notice to what I'm saying.	It's only when I really lose my temper that s/he takes any notice to what I'm saying.
I must admit that at times I find myself shouting at him/her.	I must admit that at times I find myself shouting at him/her.
I find myself nagging him/her to do more around the house.	I find myself nagging him/her to do more around the house.
When s/he says things that don't make sense, I tell him/her s/he is talking nonsense.	When s/he says things that don't make sense, I tell him/her s/he is talking nonsense.
I tell him/her that s/he must do more for him/herself if s/he wants to get better.	I tell him/her that s/he must do more for him/herself if s/he wants to get better.
EMOTIONAL OVER-INVOLVEMENT (ORIGINAL)	EMOTIONAL OVER-INVOLVEMENT (MODIFIED)
I get terribly upset when I think about his/her illness.	I get terribly upset when I think about his/her illness.
I don't know how to cope when s/he gets upset.	I don't know how to cope when s/he gets upset.
S/he knows that I worry terribly about him/her.	S/he knows that I worry terribly about him/her.
When s/he gets upset I feel so helpless.	When s/he gets upset I feel so helpless.
I do everything I can to help him/her, but I feel so powerless.	I do everything I can to help him/her, but I feel so powerless.
I sometimes think that his/her life just isn't worth living.	I sometimes think that his/her life just isn't worth living.
I worry about him everyday.	
I have gone and had a good cry about his/her situation more than once.	
When I think about him/her I get very upset.	When I think about him/her I get very upset.
It sometimes seems like our life as a family has been ruined.	

WARMTH (ORIGINAL)	WARMTH (MODIFIED)
I think it's good that we can stick together even through bad times.	
His/her illness has brought us closer together as a family.	
Despite everything, I really enjoy his/her company.	Despite everything, I really enjoy his/her company.
There are many times when it's nice for us to be together.	There are many times when it's nice for us to be together.
Since his/her illness I feel closer to him/her.	
I enjoy spending time with him/her.	I enjoy spending time with him/her.
We get on well together.	We get on well together.
We do as many things together as possible.	We do as many things together as possible.
I try to spend as much time with him/her as possible.	I try to spend as much time with him/her as possible.
There are lots of good things about him/her, even though s/he has his/her problems.	There are lots of good things about him/her, even though s/he has his/her problems.
COLLUSION (ORIGINAL)	COLLUSION (MODIFIED)
I sometimes go along with his/her funny ideas, just to keep the peace.	I sometimes go along with his/her funny ideas or behaviour, just to keep the peace.
I sometimes do things s/he asks me to do even though I know they are ridiculous.	I sometimes do things s/he asks me to do even though I know they are ridiculous.
If s/he thinks people are watching him/her or talking about him/her I sometimes pretend to check on this in order to make him/her feel better.	If s/he thinks people are watching him/her or talking about him/her I sometimes pretend to check on this in order to make him/her feel better.
I can't see anything wrong in humouring his/her funny ideas now and then.	I can't see anything wrong in humouring his/her funny ideas now and then.
If s/he says strange things I sometimes agree with him/her, even though I know they're not really true.	If s/he says strange things I sometimes agree with him/her, even though I know they're not really true.
I sometimes agree with his/her 'funny ideas' in order not to upset him/her.	I sometimes agree with his/her 'funny ideas' in order not to upset him/her.
On occasion I go along with the strange things s/he says or does, in order to reassure him/her.	On occasion I go along with the strange things s/he says or does, in order to reassure him/her.
I sometimes pretend to agree with the things s/he says, even though I know it's just his/her imagination.	I sometimes pretend to agree with the things s/he says, even though I know it's just his/her imagination.
It's best to play along with his/her ideas, as disagreeing just upsets him/her.	It's best to play along with his/her ideas, as disagreeing just upsets him/her.
In order to reassure him/her I sometimes pretend that I can hear the 'voices' too.	In order to reassure him/her I sometimes pretend that I can hear the 'voices' too.



<b>RESIGNATION (ORIGINAL)</b>	<b>RESIGNATION (MODIFIED)</b>
I don't try to cheer him/her up anymore as I've found that nothing I say makes any difference.	I don't try to cheer him/her up anymore as I've found that nothing I say makes any difference.
There is no point trying to get him/her out of bed in the morning, because nothing I do has any effect.	
I used to try and distract him/her when s/he was behaving strangely, but now I've realised that there isn't any point in doing this.	I used to try and distract him/her when s/he was behaving strangely, but now I've realised that there isn't any point in doing this.
Basically, with regard to his/her illness, I've just given up.	Basically, with regard to his/her illness, I've just given up.
I used to try and involve him/her in things, but I don't bother any more, as it doesn't help.	I used to try and involve him/her in things, but I don't bother any more, as it doesn't help.
I've given up making suggestions to him/her, as nothing makes any difference.	I've given up making suggestions to him/her, as nothing makes any difference.
I used to try talking him/her out of problems, but now I've that it doesn't help.	I used to try talking him/her out of problems, but now I've that it doesn't help.
When I think about his/her illness, I realise now that s/he'll never get any better.	When I think about his/her illness, I realise now that s/he'll never get any better.
I realise now that s/he is always going to be like this.	I realise now that s/he is always going to be like this.
I think it's best to leave it all to the doctors.	I think it's best to leave it all to the doctors.
<b>PASSIVE (ORIGINAL)</b>	<b>PASSIVE (MODIFIED)</b>
If s/he says odd or strange things, I try not to take too much notice.	If s/he says odd or strange things, I try not to take too much notice.
I just let him/her get on with his/her own life these days.	
I've found that if s/he gets upset, it's best to leave him/her to sort it out him/herself.	I've found that if s/he gets upset, it's best to leave him/her to sort it out him/herself.
If s/he wants to spend large amounts of time on his/her own, I let him/her I don't interfere.	If s/he wants to spend large amounts of time on his/her own, I let him/her I don't interfere.
Frankly, I've just got used to him/her being the way s/he is and I don't really notice it anymore.	Frankly, I've just got used to him/her being the way s/he is and I don't really notice it anymore.
I try to stay out of his/her way as much as possible.	I try to stay out of his/her way as much as possible.
I avoid saying certain things so s/he won't get upset.	I avoid saying certain things so s/he won't get upset.
When I can see that s/he's troubled I know it's best to leave him/her alone.	When I can see that s/he's troubled I know it's best to leave him/her alone.
If s/he behaves in an odd or strange way, I just accept it as part of his/her illness.	If s/he behaves in an odd or strange way, I just accept it as part of his/her illness.
It's best to leave him/her alone if s/he hears voices and to get on with things that I need to do.	It's best to leave him/her alone if s/he hears voices and to get on with things that I need to do.

<b>CONSTRUCTIVE (ORIGINAL)</b>	<b>CONSTRUCTIVE (MODIFIED)</b>
I often try to involve him/her in things I'm doing, even if s/he's not really interested in them.	I often try to involve him/her in things I'm doing, even if s/he's not really interested in them.
I often find myself encouraging him/her to do things.	I often find myself encouraging him/her to do things.
I try to take his/her mind off morbid thoughts.	I try to take his/her mind off morbid thoughts.
Sometimes I make up little jobs that don't really need doing so it will occupy him/her.	Sometimes I make up little jobs that don't really need doing so it will occupy him/her.
I try to help him/her work out what's real and what's just his/her imagination.	I try to help him/her work out what's real and what's just his/her imagination.
I try to draw him/her into conversations.	I try to draw him/her into conversations.
I suggest things to him/her that s/he might enjoy.	I suggest things to him/her that s/he might enjoy.
I remind him/her that if s/he wants to talk to someone, I'm around.	I remind him/her that if s/he wants to talk to someone, I'm around.
I try to distract him/her from the 'voices'.	I try to distract him/her from the 'voices'.
I encourage him/her to do more for him/herself.	I encourage him/her to do more for him/herself.
<b>REASSURANCE (ORIGINAL)</b>	<b>REASSURANCE (MODIFIED)</b>
I often reassure him/her that everything is going to be OK.	I often reassure him/her that everything is going to be OK.
When s/he worries about things I remind him/her that we love him/her and care about him/her.	When s/he worries about things I remind him/her that we care about him/her.
When s/he gets upset I do my best to reassure him/her.	When s/he gets upset I do my best to reassure him/her.
When s/he gets upset I try to calm him/her down.	When s/he gets upset I try to calm him/her down.
When s/he gets worried or upset I try to stay calm and remind him/her that everything will be alright.	When s/he gets worried or upset I try to stay calm and remind him/her that everything will be alright.
When s/he expresses upsetting or worrying ideas I remind him/her that we are here to help him/her.	When s/he expresses upsetting or worrying ideas I remind him/her that we are here to help him/her.
I often tell him/her that nothing bad can happen when s/he's at home with us.	I often tell him/her that nothing bad can happen when s/he's with us.
I keep reminding him/her that s/he is a good person and nobody wants to harm him/her.	I keep reminding him/her that s/he is a good person and nobody wants to harm him/her.
I try to reassure him/her that s/he can rely on our support.	I try to reassure him/her that s/he can rely on our support.

OVER-PROTECTIVENESS (ORIGINAL)	OVER-PROTECTIVENESS (MODIFIED)
I don't like him/her to be on his/her own.	I don't like him/her to be on his/her own.
I try to do most things for him/her.	I try to do most things for him/her.
I have to look after him/her, as s/he is unable to look after him/herself.	
I'm always asking him/her if s/he is OK.	I'm always asking him/her if s/he is OK.
I feel that I have to protect him/her from the outside world.	I feel that I have to protect him/her from the outside world.
I often worry how s/he would cope if I wasn't around to look after him/her.	
When people ring up to speak to him/her I try to put them off because they only upset him/her.	
It's really important to stop him/her mixing with bad company.	
I won't have alcohol in the house any more as it makes him/her feel bad.	
I think that pressurising him/her might make him/her really ill.	I think that pressurising him/her might make him/her really ill.