Illness Perceptions and Recovery Style in Schizophrenia: A longitudinal Study

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Overview

This volume comprises three sections: literature review, empirical paper, and critical appraisal. The literature review summarizes models of change which have been applied to schizophrenia (and to long-term mental difficulties in general), proposing that they may be defined by two dimensions: the level at which they focus (e.g. individual, social), and the meaning of recovery they most closely adhere to. This is then followed by a review of the literature in relation to these models. The empirical paper considers the relationship between one of these models - recovery style - and the individual's perceptions of the identity, duration, consequences, and controllability of their mental health problem. Recovery style refers to the way in which one thinks about oneself in relation to a period of mental health problems and has been conceptualized as a way of describing psychological adjustment in response to such difficulties. The final section appraises the research process, giving consideration to some of its limitations, how the stages were experienced, and what was personally gained from it.

Contents

Part I. Literature review - Models of change in schizophrenia: one for all or all for some?

Part II. Empirical paper – Illness perceptions and recovery style in schizophrenia – a longitudinal study

Part III. Critical Appraisal

Part IV. Appendices

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Part I

Literature Review

Models of change in schizophrenia:

One for all, or all for some?

Abstract

Approaches to the study and treatment of schizophrenia can be classified according to their views of 'recovery', for example what it means and how likely it is to occur. A further source of difference relates to the level at which these approaches focus e.g. the *intra*personal or *inter*personal. It is proposed that combining these provides a useful two-dimensional space in which to map out such approaches. This is illustrated in the first section using models of change in schizophrenia, which are summarized before being drawn out. In the second section, empirical data pertaining to the meaning of recovery and level of analysis in schizophrenia is reviewed and then related back to the various models of change. It is concluded that no one model of change or definition of recovery holds sway, but that instead each may have value according to the conditions that are most limiting for a particular individual e.g. symptoms, social disadvantages, or protective factors. Moreover, as these conditions change, so may the model of change or definition of recovery that it is most useful to use.

Models of change in Schizophrenia: One for all or all for some?

1. Introduction

Since its inception, the concept of schizophrenia has been surrounded by controversies regarding its nature, cause(s), course, treatment, outcome, and indeed whether it even exists at all. While some current accounts appear to give the impression that these debates have been largely resolved, these issues in fact remain the subject of much dispute in the scientific literature (e.g. Boyle, 2005; Read, Mosher, & Bentall, 2004).

One controversy relating to course has concerned the extent to which one can recover following a diagnosis of schizophrenia. However, a long-standing problem in this area has been the lack of consensus around what "recovery" actually is, with perhaps as many definitions as there are stakeholders in the area of mental health. Not surprisingly, this multitude of definitions has led to a number of models that attempt to describe the process of adjustment following a schizophrenic, or indeed any mental health breakdown.

This review will begin by considering the different meanings of recovery and how they are related to whether or not recovery is considered possible. Approaches to the study and treatment of schizophrenia have traditionally differed - explicitly or implicitly - in the degree to which they see recovery as possible. However, it will be proposed that a useful heuristic is to also consider at what level of explanation (e.g. Doise, 1986) these approaches lie; for instance whether they focus on the individual or the social context. In particular, models of the process of change following a schizophrenic breakdown will be considered in terms of their differences on these two dimensions and evidence regarding the validity and usefulness of the various ways of thinking about recovery will be reviewed.

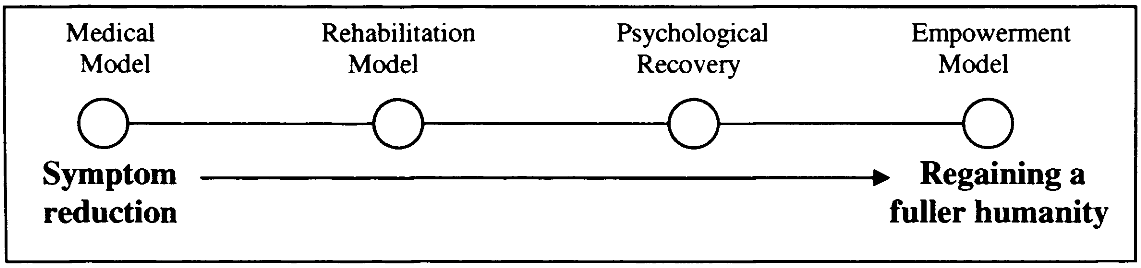
1.1 Recovery: A continuum of meanings

One source of confusion relating to the concept of 'recovery' in mental health has arisen from its use to denote both an outcome and a process (Resnick, Fontana, Lehman, Rosenheck, 2005), a discrepancy that partly reflects the two differing forces that it has arisen from: mental health professionals and the Mental Health Service user/survivor movement (Davidson, O'Conell, Tondora, Lawless, & Evans, 2005).

In the case of mental health professionals, recovery has historically been thought of in terms of amelioration of symptoms and other deficits associated with a disorder (i.e. an outcome), whereas the user/survivor moment has tended to see recovery as the journey of overcoming the effects of being a 'mental patient' e.g. loss of hope, stigma, discrimination. disempowerment, regardless of ongoing symptoms (i.e. a process). This difference may be thought of more simply in terms of the removal of 'bad' or 'negative' aspects (i.e. symptom reduction) versus the instilling of 'good' or 'positive' aspects (i.e. regaining a fuller humanity).

Fitzpatrick (2002) has suggested that different meanings of recovery might be loosely conceptualised as lying on a continuum punctuated by three major way markers: the 'medical model', the 'rehabilitative model', and the 'empowerment model', with a multitude of positions in between (Fig. 1). To these, Andreson *et al* (2003) have proposed an additional major type of model: 'psychological recovery'. The poles of this continuum can be thought of as reflecting the discrepancy above, with symptom reduction at one extreme ranging to regaining a fuller humanity at the other.

Fig 1. The recovery continuum.



Interestingly, these two poles also tend to reflect the degree to which recovery is considered possible. In a 'pure' **medical model**, mental illness is assumed to be a physical problem for which recovery means a return to the former state of health, or in other words, cure. Such an end state is not currently seen to be a possibility for most, a position exemplified by the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; APA, 1994), which states:

> "*Complete remission (i.e. a return to premorbid functioning) is probably not common in this disorder. Of those who remain ill, some appear to have a relatively stable course, whereas others show a progressive worsening associated with severe disability*"
>
> (APA, 1994).

Thus, in Fitzpatrick's continuum, the medical model holds that recovery is uncommon, with the usual prognosis being stability - or even deterioration - of symptoms, and consequent disability.

It should be noted here that while psychiatrists are usually accused of being the proponents of the medical model, many if not most would *not* claim to be adherents to a strict medical model. Indeed, given the number of times the "medical model" of course and management of schizophrenia is quoted, it is surprising how hard it is to find a paper written by an author in explicit support of it. Roberts &

Wolfson (2004) point out: *"it is a largely non-medical assertion that medical practice is governed by something called 'the medical model', and the largely non-medical recovery literature yields a strong view that psychiatric thought and practice are almost entirely hostage to it"*. Yet, although psychological and social models have increased in popularity many would argue that the medical model continues to be the predominant influence on mental health practice and services and therefore remains highly relevant.

The **rehabilitation model** is based on the medical model in that it sees schizophrenia as a (mainly) incurable medical condition or disability. However, the rehabilitation model focuses on *functioning*. With rehabilitation, disabled individuals may learn to adapt to their world and even return to something like the life they had before their mental illness (Andreson, Oades, & Caputi, 2003). In this context, recovery refers to a process of coming to terms with one's disability, adapting to its limitations, optimising residual functioning and resuming previously held social roles.

Andreson et al. (2003) suggest the addition of a further major definition of recovery – **psychological recovery** - which they believe reflects the views of most service users, and where recovery from the *psychological impact* of mental illness is emphasized. They suggest this notion would occupy a position between the rehabilitative model and the empowerment model and corresponds to "the establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self-determination". This model does not hold a position on what mental illness is or where it comes from, and is silent on whether illness is still present or not in recovery.

In contrast, the **empowerment model** makes no reference to physical substrates, instead seeing mental health problems as a combination of severe emotional distress and an interruption of a person's place in their community and social roles. In this framework, with hope and the regaining a sense of control over one's life, individuals can recover completely (Ahern & Fisher, 2001). The strong version of this model challenges the notion of continued mental illness and the necessity of medical treatment. Emphasis is placed on civil rights, returning to meaningful activity, social networks, and re-engaging with dreams and aspirations.

In summary, according to Fitzpatrick, models of recovery fall on a continuum whose extremes represent a pure 'deficit reduction' model and a pure 'empowerment' model or, in terms of prognosis, disability and full recovery. While subtle shades of meaning and difference certainly exist, stakeholders' positions can be identified according to which of the four archetypal models they resemble most closely.

1.2 A new dimension: Level of analysis

The contention of the present thesis is that the discussion around recovery can be elucidated by the addition of another dimension: level of analysis. Doise (1986) proposed that social phenomena can be studied at one of four different levels of explanation, intrapersonal, interpersonal, relational, and ideological. The *intrapersonal* level of explanation refers to psychological processes to do with an individual's organisation of their own experiences; the *interpersonal* level refers to the dynamics of relationships with other individuals in any given moment; the *positional* level of explanation relates to inter-individual interactions with emphasis on the relative social positions, or power held (e.g. status, identity); and the *ideological* level concerns wider social phenomena such as general societal beliefs and relationships between groups.

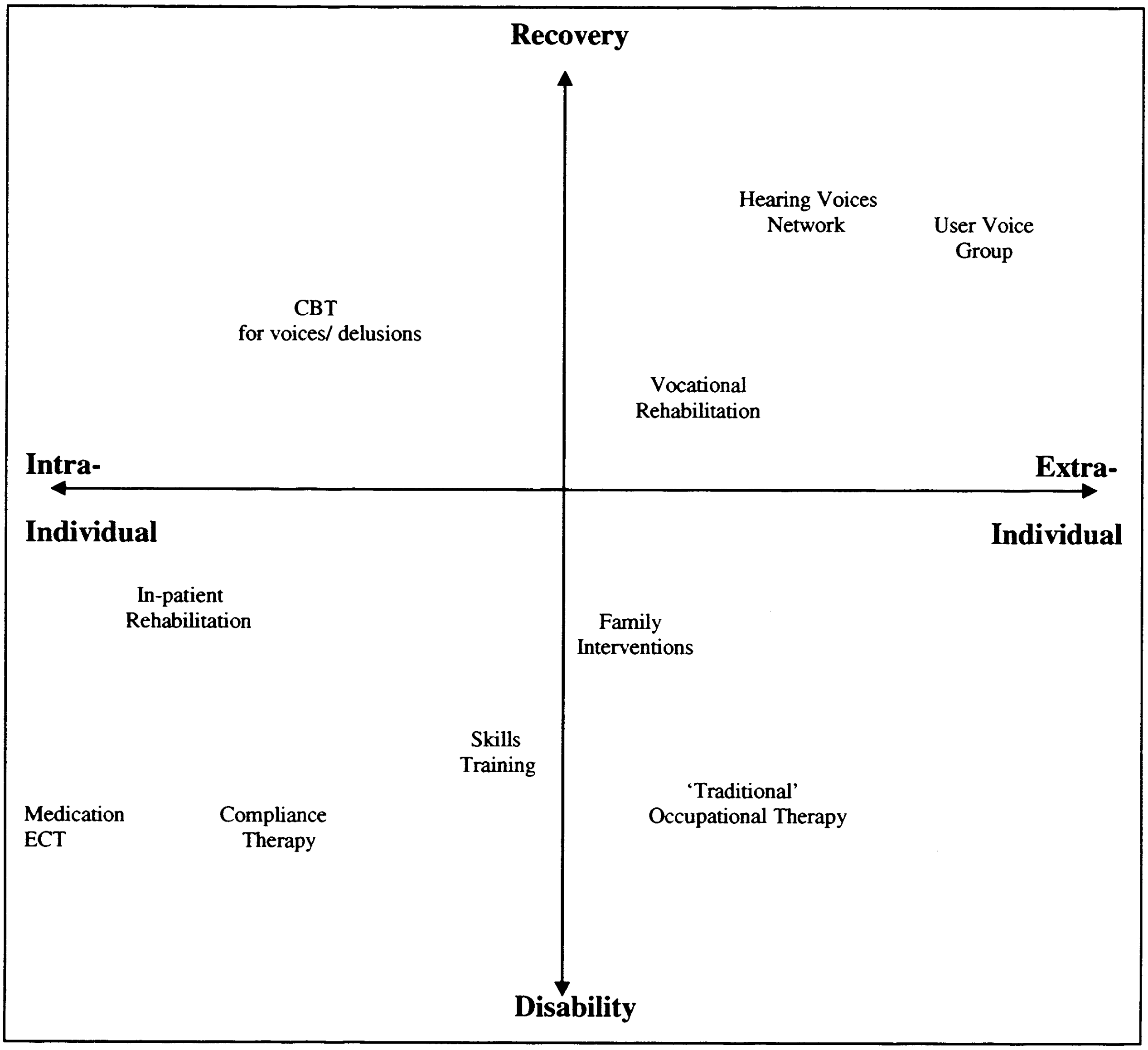
For the purposes of the present discussion, a more useful description of possible levels of explanation might be as follows: biological, psychological, interpersonal, and social levels (Table 1). Models of change in schizophrenia differ in terms of the level at which they focus. For example, the medical model predominantly describes phenomena at the biological level, whereas the empowerment model might be thought of as falling somewhere closer to the Social level.

Table 1. Levels of Analysis

Level of Analysis	Description
Biological	Includes genetics, physiology, diet, neurotransmitters, brain anatomy, physical symptoms etc.
Psychological	Beliefs & cognitions, emotions, personality, attributional style, self-confidence, self-efficacy, self-identity etc.
Interpersonal	Dynamics of relationships between people e.g. Expressed Emotion (EE), social support, social comparison, etc.
Social	Phenomena at the level of groups of people e.g. discrimination, stigma, legislation, etc.

The combining of 'levels of analysis' with the recovery continuum produces a matrix in which varying approaches to schizophrenia can be conceptually mapped out. For example, interventions in schizophrenia can be thought of both in terms of how much they aim to help an individual cope with a deficit versus getting back something they have lost, as well as at what level they aim to have an effect (Figure 2.).

Figure 2. A sample of interventions in schizophrenia: schematic representation



Cognitive Behavioural Therapy (CBT) for voices and Compliance Therapy both aim to effect change at the intrapersonal level, but differ greatly in terms of whether they see recovery as possible. Compliance Therapy focuses on deficits, or symptoms, and how the client can be helped to cope with these better (i.e. by being more compliant with medication). In contrast, CBT for voices does not see the symptom as a deficit, but instead focuses on the distressing interpretation of the experience. Since the interpretation can be altered, recovery is possible.

2. Models of change in schizophrenia

Various models have attempted to delineate processes of change in schizophrenia, or in mental health in general. In this section, current models will be summarised and their positions on the 'model of recovery' and 'level of analysis' dimensions considered. The models are presented in chronological order, for simplicity. However, they might alternatively have been clustered in terms of the type of change they refer to i.e. short to long term. While the models describe stages, or phases of change, most stipulate that not everyone will go through all stages and that the direction of movement through stages is not always linear. For each model, the definition of recovery (medical, rehabilitation, psychological, empowerment) inferred and the level of analysis at which they are situated (intrapersonal, psychological, interpersonal, psychological) will be noted.

2.1 Illness or 'medical' model

As described above, the strict 'medical' model views schizophrenia as a biological condition for which there is no cure. In such a model, the process might be conceived as occurring in stages as follows: (1) Acute phase, characterised by florid symptoms; (2) Stabilization, in which symptom remission occurs to varying extents; and (3) Relapse. Following medical terminology, some also refer to a 'prodromal' phase/stage, though the use of this is problematic, given that a proportion experiencing initial psychotic symptoms do not go on to develop a schizophrenic illness. Individuals' differing patterns of change are usually seen in terms of illness progression – 'acute' through to 'chronic' (for those with a recurring or continuous experience of symptoms) and only as 'recovery' for those whose symptoms, to a degree at least, remit. Where outcome is poor and perhaps negative symptoms remain following remission of positive symptoms there is a long, if informal, tradition amongst clinicians of talking of 'burnt out cases' (e.g. Meehl, 1962, p 829), perhaps implying neurological impairments caused by long illness.

Definition of recovery: *Medical (symptom reduction)*

Main level of analysis: *Biological*

2.2 McGlashan, Levy, & Carpenter (1975): Recovery Style

Recovery style (McGlashan, et al., 1975) relates to the particular style of coping adopted by an individual following a breakdown. While initially thought of as dichotomous, it is now usually conceptualized as a spectrum with a sealing over (avoidant) coping style at one end, and an integrating (approach) coping style at the other. Integration has been associated with more positive outcomes (e.g. McGlashan, 1987; Drayton, Birchwood, & Trower, 1998; Thompson, McGorry, & Harrigan, 2003) and there is some evidence that people will tend to move toward a more integrating style during recovery (Thompson, et al., 2003).

Definition of recovery: *Psychological*

Main level of analysis: *Psychological*

2.3 Prochaska & DiClemente (1982): Transtheoretical Model of Change

One of the most widely used models to describe processes of change is the *Transtheoretical Model of Change* (Prochaska & DiClemente, 1982). While this has been predominantly, though not exclusively, used in the field of substance misuse, it has also been applied to the study of readiness to change in severe mental illness, including schizophrenia (Rogers et al., 2001) and forms the theoretical basis of interventions such as compliance therapy. The Transtheoretical Model proposes that people go through five phases during the process of change: (1) pre-contemplation, (2) contemplation, (3) preparation, (4) action, and (5) maintenance. In pre-contemplation, a person has little awareness or desire to change, and may feel pressurised by others to do so. In contemplation, the person is aware of a problem but has not made a commitment to change. In the preparation stage, the person has decided to take action on the problem in the near future, and in the action phase they are attempting to change the problem and may be seeking help. The final stage, maintenance, is characterized by substantial and continued change of problem behaviour and by attempts to prevent relapse (Prochaska & DiClemente, 1992).

Definition of recovery:	*None*
Main level of analysis:	*Psychological*

2.4 Davidson & Strauss (1992): Rebuilding a sense of self

Davidson and Strauss (1992) focus on the rebuilding of a sense of self as an important aspect of positive change. Using semi-structured interviews to follow a sample of 66 individuals with severe mental illness (25 with a diagnosis of schizophrenia) over a 2-3 year period, they identified four basic aspects of the recovery process relevant to rebuilding and utilizing a more functional sense of self: (1) discovering the possibility of a more active sense of self; (2) taking stock of the strengths and weaknesses of this self and assessing possibilities for change; (3) putting aspects of the self into action and interpreting the results; and (4) using an enhanced sense of self to provide protection from the detrimental aspects of their condition.

The first phase involves the realization that there is another part of the self, not currently being used, that has the potential to be more active than the present self, i.e. that which is identified with the illness. This could be a dawning awareness such as that one can do better, or can have an influence on their future. In the second part of the process, the individual evaluates their strengths and limitations to see if they "have what it takes" to achieve a particular goal. Davidson & Strauss (1992) stress the importance in this phase of other peoples influence (e.g. family members, clinicians) in supporting or undermining an individual's efforts to improve - influences to which an individual is particularly vulnerable if they have a weak sense of self. In the next phase, the individual puts their new sense of self into action and then assesses the results. Depending on the success of their endeavour, their sense of self may be encouraged or undermined affecting subsequent efforts or appraisals. In relation to this stage, Davidson & Strauss (1992) suggest that efforts to obtain "compliance" with treatment as well as criticisms of efforts made, may actually have a detrimental effect on recovery by weakening a person's sense of control and self-agency. In the final stage, the more functional sense of self may be brought to bear in efforts to cope with ongoing symptoms and effects of their mental health problem, and in compensating for areas adversely affected by it.

Definition of recovery: *Between Psychological and Rehabilitation*

Main level of analysis: *Between Psychological and Interpersonal*

2.5 Diehl (1995): Emotional Stages of Recovery

Diehl (1995; cited in Baxter & Diehl, 1998) interviewed a sample of 40 consumers using a questionnaire based on constructs from the recovery literature. From this, she derived the "Emotional Stages of Recovery". Diehl's model views the recovery process as involving three psychological events followed by a stage: (1) crisis, followed by recuperation; (2) decision to "get going" followed by the rebuilding of independence; and (3) an awakening of identity and hopes followed by the building of healthy interdependence.

In the first stage, characterised by crisis and dependence on others, the predominant emotions are denial, confusion, despair, and anger. Here, an individual's needs are basic: a place of safety, food, sleep, to be looked after, and possibly also medication. The second phase begins once the person decides the crisis is over and it is time to move on. Here, the main emotions are grief for what has been lost, self-doubt, hope, anxiety, frustration, and pride. Needs at this stage are to be heard and accepted, to learn about their illness and learn skills (e.g. personal, vocational), and to have money, food, clothes, and a home. In the final stage, the person awakens to their restructured personhood after which recovery can begin. Emotions such as acceptance of self and others, confidence, and anger at injustice may be present. In this stage, the individual's needs may include dreams and aspirations, people who appreciate them, intimacy, meaningful work, fun and physical activity, and advocacy for self and others.

Definition of recovery: *Psychological*

Main level of analysis: *Between Psychological and Interpersonal*

2.6 Pettie & Triolo (1999): Meaning and identity

Pettie & Triolo (1999), in a similar way to McGlashan et al. (1975), view the integration of the illness into one's identity as critical in the task of recovery. In particular, they focus on the meaning of the experience for the individual and the centrality of social comparisons in this process. They suggest that a breakdown is followed by a period in which the person asks themselves questions such as "who am I?", "what happened?", and "why me?". During this period they may perceive two versions of themselves: who they used to be (i.e. better) and who they are now (i.e. worse), versions which will need to be reconciled if they are to move forward and construct a new identity that both includes and transcends the illness. The two tasks for the individual, therefore, are to find meaning in their experience and reconstruct their identity. Pettie & Triolo (1999) argue that the search for meaning and identity involves comparison with, and feedback from, others in the environment including other service users, friends, or those in more powerful positions such as doctors or other professionals. Whether these comparisons are accepted or rejected may depend on whether they have a positive or negative effect on one's self image. Pettie & Triolo (1999) suggest that once some meaning is found, such as the illness being seen as part of an evolutionary journey, this can then inform the original questions (e.g. "who am I?"). At this time the person can move on to the next step - "What now?" – and begin to develop a new identity and life for themselves.

Definition of recovery:	*Between Psychological and Rehabilitation*
Main level of analysis:	*Between Psychological and Interpersonal*

2.7 Young and Ensing (1999)

Young and Ensing (1999) used semi-structured qualitative interviews with 18 participants with a severe mental disorder (4 with a diagnosis of schizophrenia) to investigate the meaning and the process of recovery. Using Grounded Theory Analysis, they identified five higher order themes from their data: (1) overcoming "stuckness", (2) discovering and fostering self-empowerment, (3) learning and self-redefinition, (4) returning to basic functioning, and (5) improving quality of life.

Overcoming stuckness refers to the initial phase of the recovery process and includes acceptance of the illness, developing a desire to change, and then finding and harnessing a source of hope and inspiration. Young & Ensing (1999) comment that this appears to be the hardest part of the recovery process for many people because it involves acknowledgement of what one has lost e.g. independence.

The next, "middle phase" of recovery, involves regaining what has been lost and then beginning to move forward. Here, individuals take control and responsibility for their own life and for themselves, for example managing their mental health and stopping unhealthy habits. In addition, confidence, determination, courage, and patience may be developed. The second part of this phase involves learning new perspectives about oneself, one's illness, and the world. This bears similarities to Pettie & Triolo's (1999) work, in that a redefinition of the self and its relation to the illness may take place. The final category in the middle phase is the returning to basic areas of functioning, such as self-care, managing one's living environment, taking part in social and vocational activities, and reconnecting with social networks and one's community.

The last phase of recovery relates to improving one's quality of life and includes both striving to attain an overall sense of well being (e.g. increased self esteem, caring about things) and striving to achieve new levels of functioning (e.g. a vocation, higher standard of living, symptom reduction).

Definition of recovery:	*Between Psychological and Empowerment*
Main level of analysis:	*Psychological*

2.8 Fisher & Ahern (1999): Empowerment model of recovery

Fischer & Ahern's (1999) model of the recovery process is based around a conception of mental illness as consisting of severe emotional distress *as well as* the loss of one's place in the community and social role (Fisher, 2005). They argue that, for some, loss and trauma result in severe emotional distress such as hearing voices, paranoia, or feeling suicidal. However, these experiences do not lead to a diagnosis of mental illness if the person has sufficient support or coping resources. If these are not present, however, and the person is unable to maintain control, they are likely to enter the mental health system, lose their societal roles, and receive a mental health diagnosis, or label. Once this has happened, the task of recovery is made more difficult because the person must also recover from the "trauma" of being excluded from society and depending on benefits, as well as the original distress. Recovery in this model involves believing that one will recover, becoming involved in relationships with people who share this belief, learning recovery skills, and taking a valued role in society. However, equal emphasis is placed on gaining social empowerment. As Fisher (2006) explains:

> "For most of us consumer/survivor/ex-patients our central issues are discrimination, helplessness, and isolation. We need to overcome discrimination to gain access to the arenas of policy formation. We need to overcome our powerlessness to consistently participate in the crafting of new policies. We need to keep up our courage, and overcome the isolation and conflicts between ourselves and other disadvantaged groups in society so we can trust each other and work together. These are the elements of social empowerment, which are as important as individual empowerment.

> We need to break the image that people with psychiatric disabilities cannot contribute. That attitude has created more of a barrier to people getting or keeping a job than welfare."

Definition of recovery: *Empowerment*

Main level of analysis: *Social*

2.9 Ralph (1999): Recovery advisory group recovery model

The Recovery Advisory Group's model (Ralph, 1999) represents perhaps the most comprehensive model to date. They conceive of an individual's recovery as including the following stages: (1) Anguish, (2) Awakening, (3) Insight and action plan, (4) Commitment, and (5) Empowerment. Each of these stages consists of internal processes (i.e. what happens within oneself) and external processes (i.e. interactions with others). In addition, they sketch out external influences on the recovery process which a person may have little control over, such as policies, procedures, actions of the mental health system, financial support, housing and so on.

Definition of recovery: *Psychological - Empowerment*

Main level of analysis: *Psychological - Social*

2.10 Spaniol, Wewiorski, Gagne, & Anthony (2002)

Spaniol and colleagues (2002) conducted qualitative interviews with a group of twelve individuals with a diagnosis of schizophrenia or schizoaffective disorder over a four-year period. They identified three distinct phases of response following a breakdown, to which they added a fourth final, conceptual, stage: (1) overwhelmed by disability; (2) struggling with the disability; (3) living with the disability; and (4) living beyond the disability.

Individuals in the first phase, which begins around the time of onset of the breakdown, experience confusion, disconnectedness from their selves and from others, and a lack of power to control their lives. As people move out of this “acute” phase and into the second, they begin to develop some sort of explanation for what has been happening to them and recognise the need for developing ways to cope with their disability. This phase is characterised by the building of strength and confidence in the ability to act one’s own interests, while remaining fearful of the disability. The final phase described by Spaniol et al.’s (2002) participants was that of having come to terms with their disability and being confident about managing it. Here, people described both a stronger sense of self and a more enduring feeling of having control over their lives. Drawing on the self-help literature, Spaniol and his colleagues added a theoretical final stage where the disability was no longer a major part of the person’s life and they felt well connected to both themselves and to others, and experienced a sense of meaning and purpose in life.

Definition of recovery:	*Rehabilitation*
Main level of analysis:	*Psychological*

2.11 Andresen, Oades, & Caputi (2003): 5 stage model of recovery

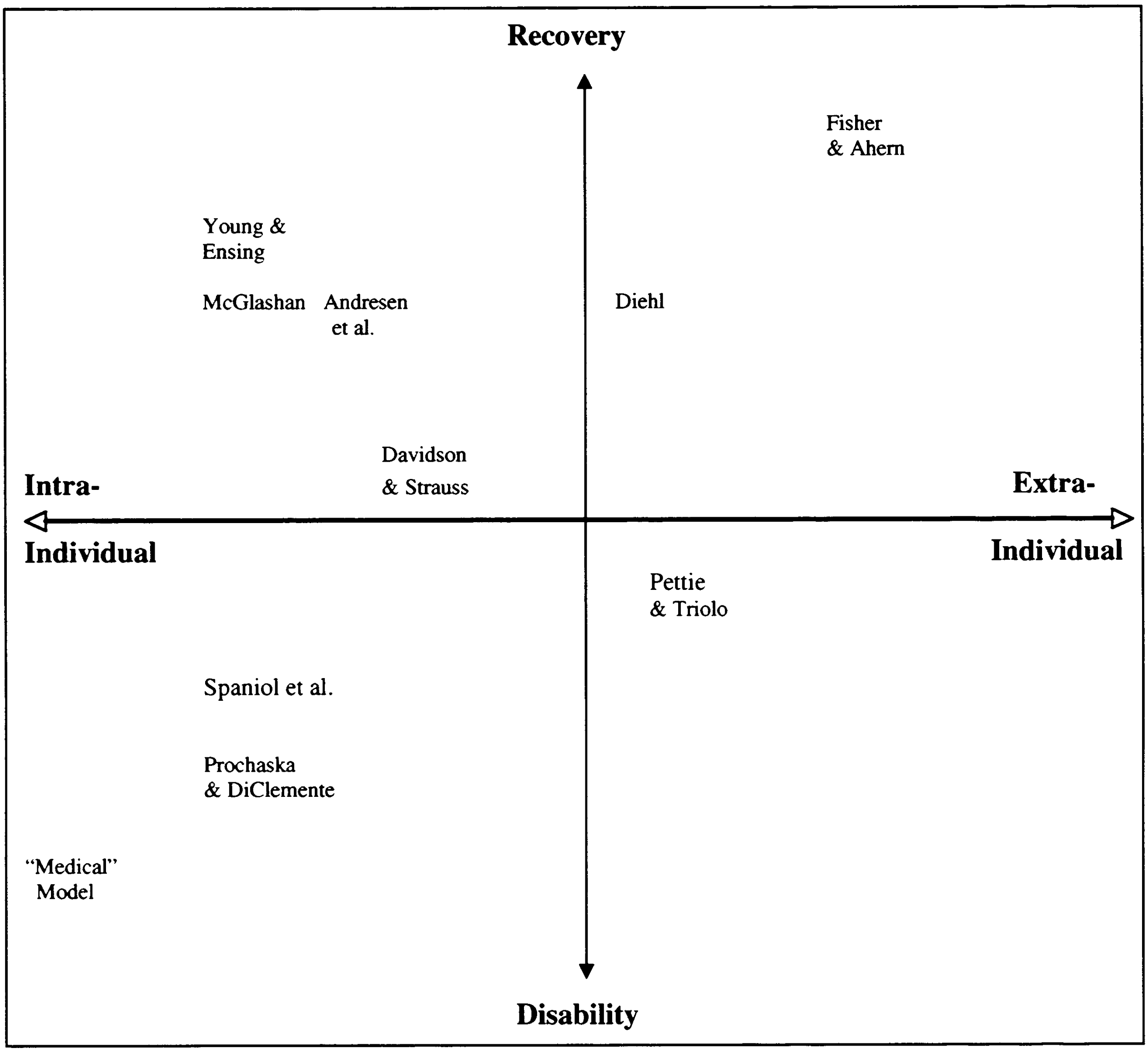
Andresen et al. (2003) reviewed and synthesized five of the qualitative studies outlined above: Davidson & Strauss (1992), Baxter & Diehl (1998), Young & Ensing (1999), Pettie & Triolo (1999), and Spaniol et al. (2000), deriving five common recovery stages: (1) Moratorium, (2) Awareness, (3) Preparation, (4) Rebuilding, and (5) Growth.

In their model, a breakdown may be followed by a moratorium, or pause, in which denial, confusion, hopelessness, identity confusion, and self-protective withdrawal may be predominant. However, some event or events – internal or external – can trigger a growing awareness that there is a better future, one of being something more than just a "sick person". Next, in preparing for change, one must take stock of one's values and resources, learn about mental illness, and acquire skills. In the rebuilding phase, the "hard work" of recovery takes place in which goals are worked towards, responsibility for oneself is assumed, and setbacks must be overcome. The final stage – growth - is viewed as the outcome of the recovery process. Andresen et al. (2003) suggest that, while a person may not be completely free of symptoms, here they know how to manage their condition and stay well, are resilient to setbacks, confident in their own ability, optimistic about the future, positive about themselves and feel that the experience has made them a better person.

Definition of recovery: *Psychological*

Main level of analysis: *Psychological*

Figure 3. Models of change



3. Empirical findings – meaning of recovery

The models of change outlined above are based upon varying ideas of how recovery should be conceptualised i.e. medical, psychological, or empowerment. A first step in considering which model of change to adopt may be to determine which of these notions of recovery has the most relevance to someone affected by schizophrenia.

One may gauge the impact of any condition in terms of how much it affects well-being and functioning. If neither of these is affected then, arguably, there is nothing to recover from. Wing and Morris (1981, p.4) state that disability in schizophrenia can arise from three sources: (1) Psychiatric impairments or dysfunctions (often described as 'symptoms'); (2) Social disadvantages (e.g. stigma, discrimination, poverty, unemployment); and (3) how one reacts to impairment and disadvantage. The degree to which each of these potential sources impacts upon well being and quality of life may therefore be relevant in assessing the suitability of each model of recovery. If symptoms account for most of the negative impact then this might support an account of recovery more centred around a medical model. Alternatively, if social disadvantages associated with severe mental illness constitute the main source of disability, an empowerment model might be favoured. In the following section the empirical data relating to these three potential sources of disability - their nature and their impact - will be reviewed.

3.1 Symptoms

It has long been recognised that the psychopathology of schizophrenia is heterogeneous and multidimensional. Put simply, this means that two individuals with a diagnosis of schizophrenia may show a different symptom profile, and within the same individual, severity of one type of symptom does not necessarily relate to severity of other symptoms.

Factor analyses of symptom checklists suggest that schizophrenia is a construct made up of five factors or dimensions (e.g. Bell et al. 1994; Lindenmayer, Bernstein-Hyman, & Grochowski, 1995; Lepin, 1991). Broadly speaking, these are: positive symptoms (e.g. hallucinations, delusions), negative symptoms (e.g. apathy, withdrawal, flattened affect), excitement (e.g. poor impulse control, hostility), cognitive deficits (e.g. deficits in abstract thinking, poor attention), and emotional distress i.e. depression and anxiety (Lykouras, Oulis, Psarros, et al., 2000). How do these symptoms change over time (do they ever go away?) and what impact do they have on an individual's life?

3.1.1 Course and Outcome

Studies that follow symptoms over time have mainly looked at psychotic (i.e. positive and negative) symptoms and cognitive deficits. Such studies are usually classed as analysing either 'course' or 'outcome' though, as Frommann (2000) notes, this differentiation is largely an artificial one, with outcome simply representing the status at some point in what might be the ongoing course of a condition (e.g. 5, 10, or 15 years after discharge). In addition, both kinds of studies may be limited in terms of the sample they use. For example, studies using participants who have already had multiple episodes of illness may provide an overly negative impression of prognosis as they miss out individuals who experience one episode only with no relapses. Nevertheless, with such limitations in mind, it is possible to gain some impression of course and outcome from the studies to date.

Course & Outcome: psychotic symptoms

The most consistent finding from follow-up studies focussing on symptomatology and disability has been heterogeneity in short and long-term outcome (Davidson & McGlashan, 1997).

In a review of 114 studies since 1801 examining outcome over 2 - 25years or longer or until death, Warner (2004) found that around 20% of people achieved ‘complete recovery’ (i.e. loss of psychotic symptoms and return to pre-illness levels of functioning) and 35-40% achieved ‘social recovery’ (“economic and residential independence and low social disruption”). These findings were supported by a recent large study, the International Study of Schizophrenia (ISOS; Harrison et al., 2001), which assessed 1633 individuals who experienced first episode psychosis from 14 international sites at 15- and 25-year follow up. They concluded that global outcomes at 15 and 25 years were favourable for over half of the people followed up and that approximately 40% of those who had a diagnosis of schizophrenia were “recovered” in terms of social and occupational functioning. In addition, 20% of those studied were able to sustain employment, despite some persisting symptoms or disability. Importantly, the study also found evidence for a ‘late recovery’ effect, that is, some people who had a poor course earlier on still showed good outcomes later.

Other studies suggest that many people will experience one episode and never relapse. For example, in the International Study of Schizophrenia Dutch Cohort (Wiersma, Nienhuis, et al., 1998; cited in Gaebel & Frommann, 2000), 33% had not experienced a relapse at 15-year follow up from first episode. Of those who had relapsed, 27% of the sample experienced full remission of symptoms between episodes, 50% partial remission, and 10% were psychotic all the time. Furthermore, outcome in third world countries appears consistently to be significantly better than in the industrialized world (WHO, 1979; Jablensky, Sartorius, Ernberg et al., 1992;

Hopper et al., 2000; Harrison et al., 2001).

The findings in terms of course paint a similar (i.e. mixed) picture. Watt, Katz, and Shepherd (1983) followed 121 individuals for a period of 5 years after their first episode of schizophrenia, describing four general courses. These included 1) one episode only and no residual impairment (16%); 2) several episodes with minimal or no residual impairment (32%); 3) residual impairment after the first episode with subsequent exacerbation and no return to normality (9%); and 4) residual impairment increasing with each episode and no return to normality (43%). However, this study was limited by its small sample size and short duration of follow up.

In a regularly cited study, Ciompi (1984; cited in Warner, 2004) retrospectively traced the histories of 228 individuals who had been admitted for treatment of schizophrenia in Switzerland throughout the twentieth century. He looked at three aspects: symptomatic onset (insidious vs. acute), course (episodic vs. continuous symptoms), and outcome ('mild or recovered' vs. 'moderate or severe'). His findings were as follows:

Onset	45% insidious	55% acute
Course	52% episodic	48% continuous
Outcome	50% mild or recovered	50% moderate or severe

In all, eight different patterns of symptomatic onset, course, and outcome were identified from onset to outcome.

Course & Outcome: cognitive deficits

Neurocognitive deficits have been studied extensively among individuals with schizophrenia and several studies have found significant differences between groups of people with schizophrenia and matched controls (Goldberg et al. 1987; Frith et al., 1991). Estimates of the proportion of those with schizophrenia who do not show neuropsychological impairments (i.e. perform in the normal range on tests) vary from 23% (Kremen et al., 2000) to 73% (Bryson et al., 1993), although evidence is accumulating that even these individuals may show a decline relative to premorbid functioning (Wilk et al., 2005).

Cross-sectional and longitudinal studies have both produced inconsistent findings with regard to how such deficits change over time (Morrison, Carroll, & McCreadie, 2006). However, cross-sectional studies are vulnerable to contamination from cohort effects and longitudinal studies may be limited in terms of how long they are able to follow their samples. However, a recent study by Morrison et al. (2006), and by far the longest study of its kind, followed up a sample of forty three individuals' 33years after they had originally been assessed. Compared to a matched control group, the schizophrenic group showed a major decline in non-verbal abstract reasoning and visuospatial problem solving abilities. While the authors concede limitations, such as how truly valid the control group was and how representative their sample was, such findings suggest that, at least for some, specific cognitive deficits may follow a downward path, albeit a relatively slow one. Whether or not such a profile reflects a consequence of schizophrenia, or iatrogenic effects such as long-term use of neuroleptic medication and social and environmental impoverishment remains to be seen.

Conclusions

While it is hard to compare and contrast these studies, the evidence in relation to symptomatic course and outcome appears to be that:

- Individuals with a diagnosis of schizophrenia differ in terms of the symptoms they experience.
- Symptoms tend to vary in an episodic fashion with a significant number appearing to experience one episode only with no relapse.
- In between episodes, levels of residual symptoms vary with some experiencing none, others continuing to have relatively high levels, and all shades in between.
- Over time, some people's symptoms will go completely, some will improve, some will not, and some will worsen.
- People may experience relatively high levels of symptoms for a number of years before recovering.
- Schizophrenia appears to be accompanied by particular cognitive deficits and, at least for some, these appear to deteriorate over time.

3.1.2 Effects of symptoms

An important question in terms of recovery is the extent to which symptoms impact on other areas of life such as occupational, social, and psychological wellbeing. Of course, for individuals who experience a single schizophrenic episode only and then return to their previous level of functioning, such questions are largely irrelevant. However, for the majority - for whom this does not appear to be the case - this question is highly important: If one can experience symptoms but no impairment then this weakens the case for a medical model of recovery. Studies investigating the negative impact of symptoms have generally looked at their relationship to either disability (i.e. limitations and restrictions on function) or quality of life (QoL). Although these concepts are undoubtedly highly related, because one is objective and the other subjective, they will be considered separately.

Symptoms & objective measures of functioning

Several studies have demonstrated that people with schizophrenia may experience difficulties in objective measures of functioning such as basic self-care, inter-personal interaction, and occupational life (e.g. Allen & Allen, 1987; Leary, Johnstone, & Owens, 1991, McGlashan, 1988).

While no studies were found which looked at the relationship between deficits in functioning in schizophrenia and excitement or emotional distress symptoms, several have investigated the influence of positive and negative symptoms and cognitive deficits. Ertugrul & Ulug (2002) have summarised nine such studies: While several found there to be an association between cognitive deficits and adaptive functioning (Allen, 1990; Breier, Schreiber, Dyer, & Picker, 1991; Penn, Mueser, et al., 1995; Kolakowska, Williams, et al., 1985), the findings regarding psychotic symptoms have been more mixed. Some studies have found an association with negative symptoms only (Kolakowska, Williams, Ardern et al., 1985; Dickerson, Boronow, et al., 1996; Van der Does, Dingemas, et al., 1993), while others have found associations with both positive and negative symptoms (Breier, et al., 1991; Ertugrul & Ulug, 2002).

Symptoms & Quality of Life

Measurements of quality of life (QoL) have become an important part of outcomes research in severe mental illness. While no definition has been universally adopted, the one common element in definitions of QoL is the individual's subjective sense of general well-being (Norman et. al., 2000).

Quality of life in schizophrenia has been found to be associated with expression of depressive and negative symptoms (Ritsner et al., 2000; Dickerson et al., 1998; Packer et al., 1998; Fitzgerald et al., 2001; Bechdolf et al., 2003) and changes in anxiety (Huppert et al., 2001) and paranoia (Ritsner et al., 2006). Severity of symptoms has been found to explain 32% (Awad et al., 1997), 19% (UK700 Group, 1999), and 10.1% (Patterson et al., 1997) of the variation in subjective QoL. In contrast with these findings, several longitudinal studies have found no significant association between severity of symptoms and subjective QoL (Barry, 1997; Kaiser & Priebe, 1998; Malla et al., 2001). In addition, Malla et al. (2001) found improvements in QoL at one year were mostly unrelated to changes in symptoms. Ritsner et al. (2006) have pointed out that these studies have been limited by small sample size and a failure to control for protective factors such as coping styles and social support. Nonetheless, this latter criticism highlights the point that the relationship between symptoms and QoL is not necessarily a linear one but is likely to be mediated by other factors.

In a recently published meta-analysis of studies investigating the influence of symptoms on quality of life, Eack and Newhill (2007) found that only small to moderate negative relationships appear to exist between various psychiatric symptoms and quality of life in schizophrenia (range r = -.20 to -.34), with general psychopathology (e.g. depression, anxiety) emerging as the largest symptomatic contributor to poor quality of life.

3.2 Social Disadvantages

As previously mentioned, the social disadvantages that can accompany schizophrenia but which are not necessarily a direct result of it include discrimination, stigma, poverty, unemployment, and homelessness. The specific impact of such disadvantages on individuals with schizophrenia has received rather less attention than that of symptoms. However, those studies that have looked at these factors indicate that they have a significant effect on sufferers' lives. For example, experiences of stigma have been found to have a number of negative consequences including reduced employability (Link et al, 1992) and difficulties in obtaining housing (Page, 1995). Sullivan et al. (1992) found that clients with mental health problems reported most dissatisfaction with the areas of finance and personal safety, whereas Skantze et al. (1992) found work, contacts with others, and money, in addition to mental health, to be the most unsatisfactory areas among a sample of outpatients. Others have found that lack of social contact, unemployment and low economic status correlated negatively with better QoL (Koivumaa-Honkanen et al., 1999).

Bjorkman and Svensson (2005) found QoL to be significantly negatively correlated with both measures of perceived rejection ($r = -0.48$) and perceived devaluation-discrimination ($r = -0.50$) in a Norwegian follow-up sample of 92 individuals with psychosis (schizophrenia = 60%). In a stepwise forward multiple regression analysis, devaluation-discrimination emerged as the third greatest contributor to variance in QoL (3%) after psychiatric symptoms (9%) and overall social network (55%). The three-factor model accounted for 67.2% of the variance in QoL scores.

Finally, the finding that individuals with schizophrenia in some third world countries tend to have better outcomes than that seen in developed countries (e.g. WHO, 1979; Jablensky, Sartorius, Ernberg et al., 1992) is of major relevance here.

Such differences almost certainly arise from culturally determined processes and, although the exact reasons are unclear, suggestions have included higher levels of family support and social inclusion, less stigmatising attitudes, and higher levels of employment (e.g. Warner, 2004). These findings suggest that the experience and occurrence of symptoms themselves, as well as their consequences, may be partially determined by social factors.

3.3 Reactions to impairment and disadvantage: Protective factors

How one responds to impairments and social disadvantages will play an important part in determining the extent of disability. Research in this area has typically looked at variables that mediate against the negative impact of schizophrenia, often termed protective factors. Those that have been found to have an impact on QoL and disability in schizophrenia include self-esteem, self-efficacy, personality traits, coping skills, social support, and temperament (Ecklund et al., 2003; Bechdolf et al., 2003; Ritsner et al., 2003; Ritsner et al., 2000; Ruggeri et al., 2001; Kemmler et al., 1999; Zissi et al., 1998; Patterson et al., 1997;). Several studies suggest that these factors account for a greater proportion of variance in quality of life than symptoms. For example, in the Norwegian study quoted above (Bjorkman and Svensson, 2005), social support accounted for 55% of the variance in QoL, while Ritsner et al. (2003) found protective factors to account for 20.9% of the variability in subjective quality of life among an Israeli sample.

Personal reactions may also play a large part in the experience of general psychopathological symptoms (such as depression and anxiety) For example, Birchwood et al. (2005) found that depression among a sample of patients with schizophrenia (N=105) was related to appraisals of the effects of the psychosis (e.g. loss, humiliation, entrapment) but not to severity of psychosis. A number of other studies have also found attributions of symptoms to play an important role in mediating coping efforts and emotional reactions (Chadwick & Birchwood, 1994; 1995; 1996). For example, Chadwick and Birchwood (1996) found beliefs about voices as being extremely powerful, or omnipotent, were related to higher depressive symptomatology. Furthermore, in the Birchwood et al. (1996) study, appraisal of one's social power and status had a major influence on voice hearers' attribution of the power and influence of voices which in turn was related to depression scores, suggesting that social factors such as stigma and discrimination play an important role in determining what impact psychiatric symptoms have on a person's life.

Summary

Schizophrenia is a heterogeneous condition in which individuals show varying symptoms at varying severities. The course and outcome of these symptoms is similarly mixed: people may experience only one episode or they may experience many. Of those who continue to experience episodes, some may completely recover between the episodes, while others experience varying levels of residual symptoms. Over time symptoms may increase or decrease and they may disappear altogether. Symptomatic recovery may occur even after years of chronicity. All symptoms, but in particular cognitive deficits and affective symptoms, appear to show a negative relationship with functioning and with quality of life, with increased severity corresponding to greater disability. However, at the group level, this relationship is modest, and in some samples psychotic symptoms have not been found to correlate with QoL at all.

Individuals with schizophrenia may also experience a number of social disadvantages such as stigma and discrimination. While these have received rather less attention than that of symptoms, these tend to be the factors that users highlight as being the biggest sources of dissatisfaction in their lives. It is also likely that such experiences play an important role in how symptoms are expressed and in how people respond to their symptoms. An area that has enjoyed significant attention in recent years relates to factors that influence one's response to impairment and disadvantages in schizophrenia. Such factors include self-beliefs, temperament, coping skills, and social support and account for a large amount of the variance in QoL studies. Significantly, protective factors appear to reduce or even eliminate the negative impact of symptoms in some individuals, suggesting that they are an integral part of recovery.

Ritsner et al. (2006) examined changes in quality of life from acute episode to around 16 months later in 148 individuals with a diagnosis of schizophrenia. The model which emerged from their data found quality of life to be predicted by baseline levels of symptoms, emotional distress, task oriented coping (problem focused), self-esteem, and friend support, accounting for 41% of the variability in

Table 2. Summary of research relating to quality of life in schizophrenia. From Ritsner et al. (2006)

Factors Associated with Quality of Life in schizophrenia	Studies finding this result
Risk factors - expression of depressive and negative symptoms - side effects of antipsychotic agents - severity of schizophrenia symptoms	Ritsner et al. (2000); Dickerson et al. (1998); Packer et al. (1998); Fitzgerald et al. (2001); Bechdolf et al. (2003)

Protective factors self-esteem, self-efficacy, coping with stressful situations, personality traits, expressed emotion and social support	Packer et al. (1998); Voruganti et al. (1997); Young et al. (1998), Ritsner et al. (2002) Awad et al. (1997), UK700 Group (1999); Ritsner et al. (2002); Ritsner et al. (2000); Bechdolf et al. (2003); Patterson et al. (1997); Kemmler et al. (1999); Ritsner et al. (2003); Eklund et al. (2003)

quality of life scores at 16 months. Changes in quality of life over time were associated with anergia, paranoid ideation, emotional distress, side-effects of neuroleptics, as well as less efficacious self-esteem, coping styles, emotional expression, and other social support.

Data such as these broadly support either a medical or psychological model, and to a lesser extent an empowerment model. It seems likely that each may be most appropriate for *some* people: For individuals with the most severe symptoms, particularly in the case of those with worsening cognitive deficits, a combined medical/psychological model may have the most utility, whereas in the case of people whose lives are most limited by stigmatization, exclusion from their local communities or from being unable to find work, an empowerment model may be more suitable.

4. Recovery from the perspective of individuals with schizophrenia

The empirical literature gives some pointers as to which models of change may be most valid. But what do sufferers themselves think about recovery? The rise of "recovery" as a legitimate concept in relation to long-term mental health problems has, after all, mainly been due to efforts on the part of individuals to publicise personal accounts of their own journey of recovery. Although it has been emphasised that "recovery" means different things to different people (e.g. Anthony, 1993; Long, 1994), such narratives clearly share many commonalities and several researchers have attempted to classify the underlying themes, most notably Ralph (2000), Corrigan et al. (2004), and Resnick et al. (2005).

In reviewing personal accounts from the recovery literature, Ralph (2000) identified four dimensions of recovery: Internal factors, Self-managed care, External factors, and Empowerment (Table 3):

Table 3 Ralph (2000): Four dimensions of recovery

Internal factors	E.g. awareness of the impact of illness, recognition of the need to change, insight about how change can begin and determination to recover
Self-managed care	An extension of the internal factors where consumers describe how they manage their own mental health and how they cope with the difficulties and barriers they face
External factors	Include interconnectedness with others, supports provided by the family, friends and professionals; and having people who believe that they can cope with and recover from their mental illness
Empowerment	A combination of internal and external factors where the internal strength is combined with interconnectedness to provide the self-help, advocacy, and caring about what happens to ourselves and to others.

Others have taken a more empirical approach, factor analysing recovery questionnaires in order to explore the core concepts involved. Corrigan et al. (2004) report results from the factor analysis of the Recovery Assessment Scale (RAS; Gifford et al., 1995), a 41-item questionnaire measuring empowerment, coping ability, and quality of life, and which was developed from analysis of recovery narratives. The RAS was administered to a sample of 1750 individuals who experienced severe mental illness. Corrigan and colleagues conducted an exploratory factor analysis on the questionnaires from half of the sample, which was then validated on the other half. Overall, five factors emerged: (1) personal confidence and hope; (2) willingness to ask for help; (3) goal and success orientation; (4) reliance on others; and (5) symptom coping. The authors noted that these factors mapped well onto the four identified by Ralph (2000; see Table 3).

Corrigan et al. (2004) also used independent measures of consumer empowerment, quality of life, hope, and meaning of life in order to test concurrent validity. Overall, hope showed the strongest relationship with all five factors, while all four of these constructs were related to more than one factor and each factor related to more than one construct. Furthermore, an inverse relationship was found between psychiatric symptoms and self-reported recovery indicating that those who were more recovered experienced fewer symptoms.

Table 4. Comparison of recovery domains

Ralph (2000)	Corrigan et al. (2004)	Resnick et al. (2005)
Internal factors	Personal confidence and hope	Hope and optimism
Self managed care and coping	Symptom coping	Knowledge
External factors	Willingness to ask for help + Reliance on others	Empowerment
Empowerment	Goal and success oriented	
		Life satisfaction

Resnick et al. (2005) used a similar technique with a sample of 1076 individuals with a diagnosis of schizophrenia. They identified 56 items which measured constructs from the existing recovery literature including various aspects of quality of life; mastery of mental health; perceptions of past, present, and future mental health; and knowledge of mental illness and services. Initial principal components analysis yielded 14 factors from which 6 were deleted due to low factor loadings or because they reflected only one item. Second order exploratory factor analysis was undertaken on the remaining 11 factors, producing a super ordinate three-factor solution which was labelled (1) hope and optimism, (2) empowerment, and (3) life satisfaction. In the subsequent confirmatory factor analysis, a better fit was produced by splitting empowerment into two separate factors: 'knowledge' and 'empowerment', giving a total of four.

It can be seen from these studies of recovery from the perspective of consumers that several interrelated themes emerge including hope and optimism for the future, confidence and ability to cope, knowledge about oneself and what support is available, a sense of control over one's life, and feeling supported and not controlled by others; findings that resonate with those from the empirical literature regarding protective factors. As Resnick and Rosenheck (2006) have highlighted, these ideas show much in common with those discussed in the positive psychology movement, a relatively recent field, based in empirical research that focuses on what makes life 'good'. Supporters of positive psychology have argued that psychology and psychiatry have for too long focused solely on that which is 'bad' (i.e. deficits and disorder) and that instead efforts should be focused on empowering people to enhance what is good in their lives rather than attend to what is wrong.

5. Conclusions: one for all, or all for some?

Schizophrenia remains one of the most controversial diagnoses in mental health despite after over 100 years of research. One such controversy, the subject of this paper, has been recovery in schizophrenia: what it means, whether it's possible, and the process by which it might happen. In fact, most ways of thinking and working with schizophrenia implicitly or explicitly adhere to one or other notion of recovery, notions which lie on a continuum from disability to full recovery. Four major conceptualizations of recovery can be demarcated: a pure medical model, in which recovery refers to cure of symptoms and is not seen as possible for most people; the rehabilitation model, where recovery is again seen in terms of symptomatic improvement, but also in terms of recovery of function; the psychological recovery model, which is indifferent to symptoms, instead referring to recovery from the psychological impact of schizophrenia; and the empowerment model which views symptoms as social constructions and focuses on recovery of lost social roles and positions which is seen as possible for all. Another important way theories and approaches to schizophrenia differ is in terms of their level of analysis, that is whether they focus at the biological, psychological, interpersonal, or social level. It was suggested that combining these two dimensions forms a useful two-dimensional space in which to conceptually map out not only models of the process of recovery, but also subjects as diverse as treatment type, service models, and theories of cause, among others.

Over recent years, a number of differing models of change in schizophrenia have been proposed. These models can be drawn out using the dimensions of recovery types and levels of analysis. While most fall somewhere between rehabilitation and psychological models of recovery, and between the psychological and social levels of analysis, notable exceptions are Fisher and Ahern's Empowerment model and the (arguably dominant) 'medical model' of recovery. Given the continuing debate around various models of recovery, and the importance of this concept in treatment efforts, attention was then turned to looking at which models were supported by the empirical evidence. The focus here was not on individual models of change, but rather on which concepts of recovery (i.e. medical, rehabilitation, psychological, or empowerment) and which level of analysis showed the most relevance and utility. To summarise, the research to date appears to indicate that symptoms, social disadvantages, and protective factors all play an important role in mediating the impact of schizophrenia on individual's lives. The data tentatively suggest that symptoms and protective factors (i.e. those relevant to medical and psychological models) play the most significant role, though the extent to which social factors influence these is unclear, particularly in the case of affective symptoms such as depression and anxiety. Perhaps the most significant message emerging from the empirical literature, however, is the heterogeneity in all of these three potential sources of disability. These findings appear to indicate that recovery is possible, but in different ways for different people and not for everybody.

This mixed picture seems to suggest that the model of recovery most appropriate will vary according to the individual, may vary within individuals over time, and may vary according to the level of analysis. For those who either experience symptoms only briefly, or who are severely disabled by them, a medical model may show the best fit with their situation i.e. cure or continuing disability. For people whose symptoms are less disabling, ways of coping may be developed, or protective factors may exist, which minimize or even eliminate the relevance of symptoms and allow a greater focus on issues such as identity and meaning in life.

For yet others, the most relevant issues in their lives may be those that arise from discrimination and disempowerment. It might be expected that, at each level of analysis, as symptoms or effects of schizophrenia decrease in severity and/or as protective factors such as coping and social support increase, people will move along the continuum from disability to recovery.

Finally, while the growth of the concept of recovery as a response to the historically pessimistic outlook in long-term mental health is to be welcomed, as Davidson and colleagues have pointed out (Davidson et al., 2005), searching for an inclusive definition of recovery that implies this is possible for all risks creating a climate of increased social pressure on people that they *must* recover, not only by taking medication to control symptoms but also by engaging - potentially prematurely or unrealistically - in new challenges and roles in order to do this. Such a future would run counter to the very core sentiment that has driven the recovery movement. Instead, as Davidson suggests, we must continuing to support and promote more conventional forms of recovery such as symptom remission, while also find ways to assist individuals to pursue their own *individual* recovery journey, appropriate to their particular needs at that moment in time.

References

Ahern, L., & Fisher, D. (n.d.). Personal assistance in community existence: PACE. Recovery at your own pace. *National Empowerment Center Newsletter,* 1–3.

Allen, C.K., & Allen, R.E. (1987). Cognitive disabilities. Measuring the social consequences of mental disorders. *Journal of Clinical Psychiatry, 48:* 185-189.

Allen, C.K. (1990) Cognitive processing and social functioning in schizophrenia. *British Journal of Psychiatry;156*:201-203.

American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders*, 4th edn. American Psychiatric Press.

Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: Towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*; *37*, 586594.

Awad, A.G., Voruganti, L.N., Heslegrave, R.J. (1997). A conceptual model of quality of life in schizophrenia: Description and preliminary clinical validation. *Quality of Life Research*; *6*: 21–26.

Baxter, E., & Diehl, S. (1998). Emotional Stages: Consumer and Family Members Recovering from the Trauma of Serious Mental Illness. *Psychiatric Rehabilitation Journal, 21,* (4). 349-355.

Bechdolf, A., Klosterkotter, J., Hambrecht, M. (2003). Determinants of subjective quality of life in post acute patients with schizophrenia. *European Archives of Psychiatry and Clinical Neuroscience*; *253*: 228–135.

Birchwood, M., Iqbal, Z., Upthegrove, R. (2005). Psychological pathways to depression in schizophrenia. *European Archives of Psychiatry and Clinical Neuroscience; 255*: 202-212.

Boyle, M. (2005). *Schizophrenia: A Scientific Delusion?* Routledge. Hove.

Bjorkman, T. & Svensson, B. (2005). Quality of life in people with severe mental illness. Reliability and validity of the Manchester Short Assessment of Quality of Life (MANSA). *Nordic Journal of Psychiatry, 59 (4):* 302-306.

Bryson, G. J., Silverstein, M. L., Nathan, A., & Stephen, L. (1993). Differential rate of neuropsychological dysfunction in psychiatric disorders: Comparison between Halstead-Reitan and Luria-Nebraska batteries. *Perceptual and Motor Skills, 76,* 305-306.

Breier, A., Schreiber, J.L., Dyer, J., Picker, D. (1991). National Institute of Mental Health Longitudinal Study of Chronic Schizophrenia: prognosis and predictors of outcome. *Archives of General Psychiatry; 48*, 239-249.

Ciompi, L. (1980). Catamnestic long term study on the course of life and aging of schizophrenics. *Schizophrenia Bulletin* 6, 606–608.

Corrigan, P.W., Giffort, D., Rashid, F., Leary, M., Okeke, I. (1999) Recovery as a psychological construct. *Community Mental Health Journal, 35(3),* 231-239.

Corrigan, P.W., Salzter, M., Ralph, R.O., Sangster, Y., Keck, L (2004). Examining the factor structure of the recovery assessment scale. *Schizophrenia Bulletin, 30 (4)*: 1035-1041.

Chadwick, P.D.J. & Birchwood, M.J. (1994). The omnipotence of voices: a cognitive approach to auditory delusions. *British Journal of Psychiatry, 165,* 190-201.

Chadwick, P. D.J. & Birchwood, M.J. (1995). The omnipotence of voices II: The beliefs about voices questionnaire.. *British Journal of Psychiatry, 166*, 11-19.

Chadwick, P. D.J. & Birchwood, M.J. (1996). Cognitive therapy for voices. In: G.Haddock & P. Slade (eds.) *Cognitive behavioural interventions for psychosis*. Routledge.

Davidson, L., O'Connell, M.J., Tondora, J., Lawless, M., & Evans, A.C. (2005). Recovery in Serious Mental Illness: A New Wine or Just a New Bottle? *Professional Psychology: Research and Practice, 36,* 5, 480-487.

Dickerson, F., Boronow, J.J., Ringel, N., Parente, F. (1996). Neurocognitive deficits and social functioning in out-patients with schizophrenia. *Schizophrenia Research;21*:75-83.

Dickerson, F.B., Ringel, N.B., & Parente. (1998). Subjective quality of life in out-patients with schizophrenia: Clinical and utilization correlates. *Acta Psychiatrica Scandinavica*; *98*: 124–127. 12.

Diehl, S. (1995). The emotional stages of recovery. In C.Talley & S. Diehl (Eds.). *BRIDGES: A journey of hope, a peer education programme for consumers of mental health services*. Knoxville: Tennessee Alliance for the Mentally Ill.

Doise, W. (1986). *Levels of Explanation in Social Psychology.* Cambridge: Cambridge University Press.

Drayton, M., Birchwood, M., & Trower, P., (1998). Early attachment experiences and recovery from psychosis. *British Journal of Consulting and Clinical Psychology, 37,* 269-284.

Eack, S.M. & Newhill, C.E. (In Press). Psychiatric Symptoms and Quality of Life in Schizophrenia: A Meta-Analysis. *Schizophrenia Bulletin.*

Ertugrul, A. & Ulug, B. (2002). The influence of neurocognitive deficits and symptoms on disability in schizophrenia. *Acta Psychiatrica Scandinavica, 105*; 196-201.

Eklund, M., Backstrom, M., Hansson, L. (2003). Personality and self variables: important determinants of subjective quality of life in schizophrenia out-patients. *Acta Psychiatrica Scandinavica,,* 108: 134–143

Fisher, D. (2005) Empowerment Model of Recovery From Severe Mental Illness: An Expert Interview With Daniel B. Fisher, MD, PhD. *Medscape Psychiatry & Mental Health 10(1).*

Fisher, D. (2006). The empowerment model of recovery: Finding our voice and having a say. *The National Empowerment Centre.* http://www.power2u.org

Fitzpatrick, C. (2002). A New Word in Serious Mental Illness. *Behavioural Healthcare Tomorrow.* 11(4).

Fitzgerald, P.B., Williams, C.L., & Corteling, N. (2001). Subject and observer-rated quality of life in schizophrenia. *Acta Psychiatrica Scandinavica,* 103: 387–392.

Frith, C.D., Leary, J., & Cahill, C. (1991). IV. Performance on psychological tests: demographic and clinical correlates of the results of these tests. *British Journal of Psychiatry; 159,* (Suppl. 13), 26-29.

Goldberg, T.E., Weinberger, D.R., & Berman, K.F. (1987). Further evidence of dementia of prefrontal type in schizophrenia? A controlled study of teaching the Wisconsin Card Sorting Test, *Archives of General Psychiatry, 44,* 1008-1014.

Hafner, H. (2005). Schizophrenia and depression. *European Archives of Psychiatry and Clinical Neuroscience; 255*: 157-158.

Harrison, G., Hopper, K., Craig, T., Laska, E., Siegel, C., Wanderling, J., Dube, K.C., Ganev, K., Giel, R., van der Heiden, W., Holmberg, S.K., Janca, A., Lee, P.W., Leon, C.A., Malhotra, S., Marsella, A.J., Nakane, Y., Sartorius, N., Shen, Y., Skoda, C., Thara, R., Tsirkin, S.J., Varma, V.K., Walsh, D., Wiersma, D. (2001) Recovery from psychotic illness: a 15- and 25-year international follow-up study. *British Journal of Psychiatry*;178:506-17.

Hogg, M.A. & Vaughan, G.M. (1998). *Social Psychology* (2nd Edition). London: Prentice Hall.

Hopper, K. & Wanderling, J. (2000). Revisiting the developed versus developing country distinction in course and outcome in schizophrenia: results from ISoS, the WHO collaborative follow-up project: International study of schizophrenia. *Schizophrenia Bulletin* ;26(4):835-46.

Kemmler, G., Meise, U., & Tasser, A. (1999) Subjective quality of life of schizophrenic patients. Effects of treatment setting, psychopathology and extrapyramidal motor drug effects. *Psychiatric Praxis*; 26: 9–15.

Koivumaa-Honkanen, H.T., Honkanen, R. & Antikainen, R. (1999). Self-reported life satisfaction and treatment factors in patients with schizophrenia, major depression and anxiety disorder. *Acta Psychiatrica Scandinavica, 99*: 377–384.

Kolakowska, T., Williams, A.O., Jamber, K., Andem, M. (1985). Schizophrenia with good and poor outcome. 3. Neuro-logical `soft signs', cognitive impairment and their clinical significance. *British Journal of Psychiatry;146*:348-357.

Kolakowska, T., Williams, A.O., Ardern, M., Jambor, K. (1985). Schizophrenia with good and poor outcome. I. Early clinical features, response to neuroleptics and signs of organic dysfunction. *British Journal of Psychiatry;146*:229-239.

Kremen, W. S., Seidman, L. J., Faraone, S. V., Toomey, R., & Tsuang, M. T. (2000). The paradox of normal neuropsychological function in schizophrenia. *Journal of Abnormal Psychology, 109,* 743–752.

Kunikata, H. & Mino, Y. (2003). Quality of life and schizophrenia: a review of the literature. *Japanese Journal of Public Health, 50* (5), 377-388.

Leary, J., Johnstone, E.C., & Owens, D.G.C. (1991). Social Outcome. *British Journal of Psychiatry, 159,* (Supplement 13): 13-21.

Link, B.G., Cullen, F., Mirotznik, J., Struening, E. (1992). Consequences of stigma for those with mental illness: evidence from social sciences. In Fink, P.J., Tasman, A. (eds). *Stigma and Mental Illness.* American Psychiatric Press, Washington DC, pp 87-96.

Long, A.K. (1994). Reflections on recovery. In *Recovery: The new force in mental health.* Columbus, OH: Ohio Department of Mental Health.

Maslow, A.H. (1943). A Theory of Human Motivation. *Psychological Review*, 50, 370-396.

McGlashan, T.H., Levy, S.T., Carpenter, W.T. (1975). Integration and Sealing Over. *Archives of General Psychiatry, 32.*

McGlashan, T. H. (1988). A selective review of recent North American long-term follow-up studies of schizophrenia. *Schizophrenia Bulletin, 14,* 515–542.

Morrison, G., O'Carrol, R., & McCreadie, R. (2006) Long-term course of cognitive impairment in schizophrenia. *British Journal of Psychiatry 189*: 556-557.

Norman, R.M.G., Malla, A.K., McClean, T., Panth, L., Voruganti, N., Cortese, L., McIntosh, E., Cheng, S, Rickwood, A. (2000). The relationship of symptoms and level of functioning in schizophrenia to general well-being and the Quality of Life Scale. *Acta Psychiatrica Scandinavica, 102*: 303-309.

Packer, S., Husted, J., Cohen, S., & Tomlinson, G. (1998). Psychopathology and quality of life in schizophrenia. *Journal of Psychiatry and Neuroscience*; 22:

231–234.

Page, S. (1995). Effects of mental illness label in 1993: acceptance and rejection in community. *Journal of Health and Social Policy, 7*: 61-68.

Patterson, T.L., Shaw, W., & Semple, S.J. (1997). Health-related quality of life in older patients with schizophrenia and other psychoses: relationships among psychosocial and psychiatric factors. *International Journal of Geriatric Psychiatry*; 12: 452–461.

Penn, D.L., Mueser, K.T., Spaulding, W., Hope, D.A., Reed, D. (1995). Information processing and social competence in chronic schizophrenia. *Schizophrenia Bulletin;21*:269-281.

Pettie, D., & Triolo, A. M. (1999). Illness as evolution: The search for identity and meaning in the recovery process. *Psychiatric Rehabilitation Journal, 22*(3), 255–263.

Prochaska, J.O., DiClemente, C.C.. (1982). Transtheoretical therapy: toward a mode integrated model of change. *Psychotherapy: Theory, Research, and Practice, 19* (3), 276-287.

Prochaska, J.O., DiClemente, C.C., & Norcross, J.C. (1992) In search of how people change : Applications to addictive behaviors. *American Psychologist*, 47, 1102–1114.

Ritsner, M., Gibel A., & Ratner, Y. (2006). Determinants of changes in perceived quality of life in the course of schizophrenia. *Quality of Life Research 15*: 515–526.

Ralph, R. O., & The Recovery Advisory Group. (1999). The recovery advisory group recovery model. *National Conference on Mental Health Statistics.* http://www.mhsip.org/recovery/index.html

Read, J., Mosher, L., & Bentall, R. (2004). *Models Of Madness: Psychological, Social, and Biological Approaches to Schizophrenia.* Routledge, Hove.

Rogers, S., Martin, R., Anthony, W., Massaro, J., Danley, K., Crean' T., & Penk, W. (2001). Assessing Readiness for Change Among Persons with Severe Mental Illness. *Community Mental Health Journal*, 37, 2, 97-112.

Resnick, S.G., Fontanna, A., Lehman, A.F., Rosenheck, R.A. (2005).. An empirical conceptualization of the recovery orientation. *Schizophrenia Research, 75*: 119-128.

Ralph, R.O. (2000). Review of Recovery Literature: Synthesis of a Sample of Recovery Literature. *National Technical Assistance Centre for State Mental Health Planning (NTAC).* Alexandria, VA.

Ritsner, M., Modai, I., & Endicott, J. (2000). Differences in quality of life domains, psychopathological and psychosocial factors in psychiatric patients. *Journal of Clinical Psychiatry*; 61:880–889.

Ritsner, M., Ponizovsky, A., & Endicott, J., (2002). Relatively small impact adverse events of antipsychotics on life satisfaction of schizophrenia patients: A naturalistic study. *European Neuropsychopharmacology*; 12: 31–38.

Ritsner, M., Ben-Avi, I., Ponizovsky, A., Timinsky, I., & Modai, I. (2003) Quality of life and the coping with schizophrenia symptoms. *Quality of Life Research*; 12: 1–9.

Ritsner, M., Modai, I., Endicott, J., Rivkin, O., Nechamkin, Y., Barak, P., Goldin, V., Ponizovsky, A. (2000). Differences in quality of life domains, psychopathological and psychosocial B.factors in psychiatric patients. *Journal of Clinical Psychiatry*; 61:880–889.

Ritsnner, M., Farkas, H., & Gibel, A. (2003). Satisfaction with quality of life varies with temperament type of patients with schizophrenia. *Journal of Nervous and Mental Disorders, 191*: 287-294.

Ruggeri, M., Bisoffi, G., Fontecedro, L., Warner, R. (2001) Subjective and objective dimensions of quality of life in psychiatric patients: A factor analytical approach: The South Verona Outcome Project 4. *Br J Psychiatry*. 178:268–275.

Spaniol, L., Wewiorski, N.J., Gagne, C., & Anthony, W.A. (2002). The process of recovery from schizophrenia. *International Review of Psychiatry, 14*, 327-336.

Thompson, K., McGorry, P.D., & Harrigan, S.M. (2003). Recovery style and outcome in first episode psychosis. *Schizophrenia Research 62*. 31-36.

UK700 Group. Predictors of quality of life in people with severe mental illness. Study methodology with baseline analysis in the UK700 trial. Br J Psychiatry 1999; 175: 426–432.

Van Der Does A.J.W., Dingemas, P.M.A.J., Linszen, D.H., Nugter, M.A., Scholke, W.F. (1993). Symptom dimensions and cognitive and social fonctioning in recent onset schizophrenia. *Psychological Medicine;23*:745-753.

Voruganti LN, Heslegrave RJ, Awad AG. Quality of life measurement during antipsychotic drug therapy of schizophrenia. J Psychiatry Neurosci 1997; 22: 267–274.

Varma, V.K., Walsh, D., Wiersma, D. (2001) Recovery from psychotic illness: a 15- and 25-year international follow-up study. *British Journal of Psychiatry, 178*. 506-517.

Warner, R. (2004). *Recovery from Schizophrenia: Psychiatry and Political Economy.* Routledge, New York.

Wilk, C.M., Gold, J.M., McMahon, R.P., Humber, K., Iannone, V.N., Buchanan, R.W. (2005). No, it is not possible to be schizophrenic yet neuropsychologically normal. *Neuropsychology, 19* (6): 778-786.

Young, A.S., Sullivan, G., & Burnam, M.A. (1998). Measuring the quality of outpatient treatment for schizophrenia. *Archives of General Psychiatry*, 28: 1221–1230.

Young, S.L., & Ensing, D. S. (1999). Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal, 22,* 219–231.

Zissi, A., Barry, M.M., Cochrane, R. (1998). A mediational model of quality of life for individuals with severe mental health problems. *Psychological Med*icine, 28:1221–1230.

Part II

Empirical Paper

Illness perceptions and recovery style in schizophrenia: A longitudinal study

Abstract

Background. Illness perceptions have been found to predict coping in physical health and to a lesser extent in mental health. Recovery style refers to psychological adjustment following a breakdown and has been found to predict outcome. This study examines the relationship between illness perceptions, recovery style and outcome.

Methods. 31 people with a schizophrenia spectrum disorder were assessed at two time points, 6-months to two years apart. Measures included illness perceptions, recovery style, symptom severity, engagement, impairment, and quality of life.

Results. Illness perceptions were not related to recovery style, but were predictive of quality of life and engagement. A change in recovery style was associated with a change in level of impairment.

Conclusions. Illness perceptions do not appear to mediate the relationship between early experiences and recovery style, but have important relationships with outcome. The findings support a psychosocial approach to working with severe and enduring mental health problems.

Introduction

Overview

The notion of recovery in serious mental illness has become one of the major organizing concepts in the formation of mental health policy and delivery of services in recent years (Davidson et al., 2005). Models of recovery emphasise psychological adjustment following a psychotic breakdown as an important part of the recovery process (e.g. Andresen, Oades, & Caputi 2003; Diehl, 1995; Pettie & Triolo, 1999; Ralph, 1999; Spaniol et al, 2002; Young & Ensing, 1999). One way in which variations in psychological adjustment have been conceptualized is in terms of Recovery Style (McGlashen, Levy, & Carpenter, 1975), which refers to how one thinks about oneself in relation to the psychotic episode. Recovery styles characterized by a tendency to explore the meaning of the experience and how it relates to one's continuing sense of self have been associated with more positive outcomes than those in which people tend to avoid thinking about it. This has lead to suggestions that therapeutic interventions aiming to promote recovery and improve long-term outcome could do so by altering recovery style (Thompson et al., 2003).

During recent years, the "cognitive revolution" has seen attention turn to the role of appraisals in mediating emotional, behavioural, and cognitive responses to events raising hopes that adaptive responses may be encouraged through the targeting of appraisals. Indeed, appraisals of health threats, or 'illness perceptions', have been widely investigated in the field of physical health where they have been found to predict emotional responses to illness, health-related behaviour (e.g. treatment adherence) and relationships with healthcare providers (Salmon, 2002). Furthermore, there is evidence that altering individual's appraisals of their illness impacts on coping and outcome (Petrie et al. (2002). More recently, the importance of such beliefs has also been associated with emotional and coping responses to mental health problems (Watson, et al., 2006; Lobban, Barrowclough, & Jones, 2004). If recovery style represents a coping response to the experience of psychosis, then appraisals of mental health problems may also play an important part in determining which recovery style an individual adopts and may represent a focus for interventions designed to improve outcomes.

Recovery Style

In their original formulation, McGlashan and colleagues (McGlashan, 1987; McGlashan & Carpenter, 1981; McGlashen, Levy, & Carpenter, 1975) described individual adjustment following an episode of psychosis as following either an 'integrating' or 'sealing over' recovery or coping style. Originally conceived of as distinct coping traits, stable over time, these two styles are now considered to reflect extremes of a continuum of coping styles, and have been found to be changeable over time (Jackson et al., 1998; Tait et al., 2003; Thompson et al., 2003).

An 'Integrating' recovery style as been defined as an awareness of the psychological continuity between one's self before a psychotic experience, through that experience, and then beyond into the recovery phase. Individuals who adopt this style assume responsibility for their thoughts and actions while psychotic, and show awareness of both the pleasurable and the painful aspects of the experience. Furthermore, these experiences are used as a source of information about oneself; one's conflicts, relationships, and behaviour (McGlashan, 1987). In essence then, an integrating recovery style involves an acceptance and ownership of ones psychotic experiences coupled with a willingness to reflect and learn from the episode.

In contrast, with a sealing over recovery style the individual distances oneself from the psychotic episode. Whereas an individual with an integrating recovery style may relate their psychotic productions to previous life stresses or conflicts, in sealing over these experiences are viewed as causally independent interruptions to one's life. As such, there is reluctance to think about or explore the meaning of one's symptoms whilst an awareness of the negative aspects of the experience is retained. Individuals who employ a sealing over recovery style may therefore consciously or unconsciously avoid thinking about their psychotic experience and desire to 'put the experience behind them'.

Sealing over has been associated with poorer outcome on a number of measures. These have included relapse (McGlashan, 1987), social functioning (McGlashan, 1987), depression (Drayton et al., 1998; Tait et al., 2004), quality of life at 6-month follow up (Tait et al., 2004) and 12-month follow-up (Thompson et al., 2003), and psychopathology at 12-month follow up (Thompson et al., 2003). Furthermore, sealing over has been found to be predictive of poorer service engagement (Tait et al., 2003, 2004) although interestingly does not appear to be related to measures of insight (Drayton et al., 1998; Tait et al., 2003) suggesting that is it possible for one to show an awareness of one's psychotic episode but want to avoid thinking about it.

Various authors have argued that adaptation to psychosis is mediated by attitudes, inferences, and evaluations about oneself and one's illness, which are in turn derived from early experiences (Chadwick, Birchwood, & Trower, 1996; Drayton, 1995). For example, Birchwood et al., have demonstrated that individuals' appraisal of psychosis and its implications for their future and identity are critical to their adjustment and predict later depression (Birchwood et al., 2000*a,b*). Such models therefore suggest that adjustment and coping in the face of psychosis is influenced by appraisals of oneself and of the impact of the psychosis.

Illness Perceptions

The role of appraisals in determining coping responses has received considerably more attention in the physical health literature where one influential model has been the Self-Regulation Model (SRM; Leventhal, Nerenz, & Steel, 1984). The SRM assumes that people are active problem solvers whose health related behaviours are attempts to bring them closer from their perceived current state to their desired future state. The model suggests that individual's coping strategies are influenced by the mental representations they have of their illness, termed 'Illness Perceptions'. Illness Perceptions represent 'common sense' schemas or explanatory models about health threats that vary along five dimensions: (1) their *identity* or the label for the threat (e.g. 'schizophrenia') and its symptoms (e.g. paranoia, hearing voices); (2) their *time-line* i.e. how long it takes for the disease to develop, it's duration, and the length of recovery; (3) the *cause* (e.g. genes, drug use, etc); (4) the *consequences*, real and imagined (e.g. being sectioned, losing one's mind, etc); and (5) *control* i.e. the perception of the degree to which the disease can be influenced or cured.

The SRM has been operationalized in the form of the Illness Perceptions Questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996), which includes scales to assess these five types of key beliefs. Scores on the IPQ have been found to predict responses to chronic illnesses including attendance for rehabilitation following myocardial infarction (MI, Petrie *et al,* 1996), recovery from Chronic Fatigue syndrome (Moss-Morris & Chalder, 2003), and adjustment to Multiple Sclerosis (Jopson & Moss-Morris, 2003). A meta-analytic review, covering 45 studies, found perceptions of controllability/curability to be positively related to psychological well being, social functioning, and vitality, and negatively related to psychological distress. In contrast, illness consequences, time-line, and identity showed negative associations with psychological well being, role and social functioning, and vitality (Hagger & Orbell, 2003). Importantly, in one of the few studies to look at interventions, Petrie *et al* (2002) demonstrated that illness perceptions among a group of MI patients could be altered leading to fewer reported symptoms and a faster return to work relative to a control group.

The IPQ has been applied unmodified in two studies of individual's with psychosis. Clifford (1998) used the IPQ with a sample of 38 individuals with psychosis, finding acceptable levels of internal reliability (αs = .60 - .92) for the IPQ subscales. Individual's who perceived fewer and less severe symptoms, shorter duration of illness, external cause, and more severe negative consequences of having schizophrenia were less likely to adhere to prescribed medication. However, Talley (1999) found only the consequence and symptom subscales to be internally reliable, with the consequence subscale also showing some concurrent validity with other measures of illness impact.

A more recent version of the IPQ has been developed, the Illness Perceptions Questionnaire – Revised (IPQ-R; Moss-Morris et al., 2001), which includes additional sub-scales: 'timeline cyclical' (how variable symptoms are) and 'coherence' (how much individual's believe they understand their illness) and is specifically designed to be modified to suit particular illnesses. Watson et al. (2006) used the IPQ-R to assess a sample of people with non-affective psychosis, finding illness perceptions to account for 46, 36, and 34% of the variance in depression, anxiety, and self-esteem respectively. In particular, the IPQ sub components of high symptom scores, a longer timeline, a higher level of perceived consequences, and a low level of cure/control were significantly related to higher levels of depression, anxiety, and lower levels of self-esteem. Lobban, Barroclough, and Jones (2005) have adapted the IPQ-R further for specific use with individuals with a diagnosis of schizophrenia (Illness Perception Questionnaire for Schizophrenia; IPQS). The IPQS retains the five subscales of the IPQ (identity, time-line, cause, consequences, control) but includes the dimensions of personal control (over one's condition), treatment control (over the condition), personal blame, illness coherence (how much one feels they understand their condition), and emotional representation (the amount of distress felt to be caused by the condition). Using the IPQS, Lobban et al. (2004) found beliefs about mental health among a sample of individuals diagnosed with schizophrenia to be significant predictors of outcome in terms of anxiety, depression, quality of life, self-perceived mental health, and disability. Beliefs about negative consequences showed the strongest relationship with outcome, with coherence beliefs also being an important predictor of depression.

Aims

In summary, recovery style describes the process of psychological adaptation following an episode of psychosis and is conceptualized as a coping continuum with an integrating (approach) coping style at one extreme and a sealing over (avoidant) coping style at the other. Sealing over has been associated with worse outcomes on a variety of indices, as well as more negative childhood experiences and low personal resilience. It has been hypothesized that sealing over is motivated by appraisals of psychosis as being too painful or threatening to one's sense of self. One way in which appraisals of health threats have been described is in terms of 'illness perceptions', which have themselves been related to a variety of outcomes. This study aims to investigate the relationship between recovery style, illness perceptions, and outcome over time. Specifically, if both recovery style and illness perceptions are related to outcome then recovery style may represent a mediating variable between illness perceptions and outcome:

Illness Perceptions ⟶ *Recovery Style* ⟶ *Outcome*

Hypotheses

Following Baron and Kenny (1986) and Judd and Kenny (1981), hypotheses necessary for testing a mediational hypothesis are as follows:

1. *Illness perceptions and outcome*

That the initial variable (illness perceptions) at time 1 will predict outcome. Specifically, perceptions of personal control (IPQ-personal control) and treatment control (IPQ-treatment control) at time 1 will be related to higher quality of life and less impairment at time 2, while perceptions of worse consequences (IPQ-Consequences), external cause (IPQ-external), poor understanding of one's condition (IPQ-coherence), higher levels of symptoms (IPQ-identity), longer timeline (IPQ-chronic), and higher levels of emotional distress (IPQ-emotional representation) at time 1 will be related to higher impairment and lower quality of life at time 2.

2. *IPQ and Recovery Style*

That the initial variable (illness perceptions) will be related to the hypothesized mediator (recovery style). That is, perceptions of personal control (IPQ-personal control) and treatment control (IPQ-treatment control) at time 1 will predict a more integrating recovery style at time 2, whereas perceptions of worse consequences (IPQ-Consequences), external cause (IPQ-external), a poor understanding of one's condition (IPQ-coherence), higher levels of symptoms (IPQ-identity), longer timeline (IPQ-chronic), and higher levels of emotional distress (IPQ-emotional representation) at time 1 will predict a more sealing over style at time 2.

3. Recovery style and outcome

That the hypothesized mediating variable (recovery style) at time 1 will predict outcome at time 2. Specifically, a more integrating style at Time 1 will be positively associated with quality of life and engagement and negatively associated with functional impairment at Time 2.

4. *Illness perceptions, recovery style, and outcome*

That the effect of the initial variable (illness perceptions) on the outcome variables will be zero when controlling for the hypothesised mediator variable (recovery style).

Method

Design

A longitudinal and cross sectional design was used to investigate Illness Perceptions and Recovery Style over a six month to two year period (For an explanation of data collection unique to this study see Appendix 6).

Participants

Participants were recruited through an inner London Mental Health and Social Care Trust's Rehabilitation and Residential Mental Health Service. Criteria for inclusion were a clinical diagnosis of a DSM-IV Axis-I psychotic disorder, and being between the ages of 18 and 65 years. Participants with a history of organic brain damage, or who were judged to be too acutely unwell at the time of data collection were excluded. A total of 112 people were initially identified as eligible. Of these, 50 people (14 female, 36 male) agreed to take part in the study at Time 1 and those who agreed were followed up 6-24 months later. Personal information such as diagnosis, length of contact with services, and recent history was taken from medical notes after written consent was obtained from each participant.

Measures

Brief Psychiatric Rating Scale (BPRS)

The BPRS (Overall & Gordon, 1962; Appendix 5) is a widely used measure of symptom severity in many psychiatric disorders, predominantly schizophrenia, and has good reliability and validity (Ventura, Green, Shaner, & Liberman, 1993). The expanded version for schizophrenia (Luckoff, Liberman, & Nuechterlein, 1986) was used in this study, which consists of 24 items, each rated on a scale from 1-7 with a higher score indicating higher levels of current symptomatology.

Bexley Engagement Scale (BES)

The BES (Wolfson & Cupitt, 2001; Appendix 5) is a six-item measure of service users' engagement with mental health services. Designed for use with people with severe mental health problems, it takes into account that people can be in contact with services but not agree with them and vice versa. Responses are scored on a scale of 0-4, with higher numbers indicating a higher degree of engagement.

Life Skills Profile (LSP)

The LSP (Rosen, Hadzi-Pavlovic, & Parker, 1989; Appendix 5) is a measure of current functioning and disability and was used to assess impairments in skills of daily living and social interactions. The LSP consists of sub-domains: self-care, turbulence, social contact, appropriateness and responsibility although only the overall score was used here. The 39-item long version was used for this research. The LSP is a widely used measure and has been shown to have good reliability and validity. Higher scores indicate higher levels of disability.

Manchester Short Assessment of Quality of Life (MANSA)

The MANSA (Prieb, Huxley, Knight, & Evans, 1999; Appendix 4) is a 25-item questionnaire used to assess quality of life in people with mental illness. The scale comprises of 14 demographic items related to quality of life and 11 items that assess satisfaction with well being in areas such as relationships, accommodation, occupation, and physical and mental health. The MANSA has been shown to have satisfactory reliability and validity (Bjorkman & Svensson, 2005). Higher scores indicate higher levels of satisfaction.

Recovery Style Questionnaire (RSQ)

The RSQ (Drayton et al., 1998; Appendix 4) consists of 39 statements which respondents score as either 'agree' or 'disagree' and measures whether individuals tend toward either an Integrating or a Sealing-over Recovery Style. Responses are scored as 1 if they are in the direction of Integration, or 0 if they are in the direction of Sealing-over; higher scores denote an increasing tendency toward an integrating Recovery Style.

The RSQ was originally scored such that respondents fell into one of four groups (Sealing-over, tending toward Sealing-over, tending toward Integrating, and Integrating) in order to create a bi-modal distribution (Drayton et al., 1998), reflecting the dichotomous conceptualization of recovery style. However, in light of the current understanding of Recovery Style as a continuum rather than a personality trait, this study scored the RSQ as a continuous construct, with a maximum score of 39.

Illness Perceptions Questionnaire for Schizophrenia (IPQ-S)

The IPQ-S (Lobban et al., 2005; Appendix 4) is an adapted version of the Illness Perceptions Questionnaire (IPQ; Weinmann et al., 1996) that has been specifically modified for use with individuals with a diagnosis of schizophrenia. Cronbach's alphas for the sub-scales range from .57-.95 (Lobban et al., 2002) and all sub-scales show good reliability and validity. The sub-scales are summarised here and the items are listed in Appendix 4.

* Identity (58 items). Fifty-eight mental health experiences associated with schizophrenia are listed including positive symptoms, negative symptoms, affective symptoms, and side effects of medication. Respondents are asked which of these they have experienced and, for those they have, whether they attributed it to a mental health problem, effects of medication, and/or other factors. The three identity scales

are scored by calculating the proportion of endorsed symptoms attributed to each of the three possible causes.

The remaining subscales all consisted of statements that were scored between 1 (strongly disagree) and 5 (strongly agree).

* Timeline acute/chronic (6 items)
* Consequences (11)
* Personal control (4)
* Personal blame (3)
* Treatment control (5)
* Coherence (5)
* Emotional representation (9)
* Cause –internal (10)
* Cause – external (4)
* Cause – biological (4)
* Cause – powerful others (8)

High scores denote a more chronic or cyclic timeline, greater perceived negative consequences, greater perceived personal control and belief in treatment, and a sense of having a less coherent understanding. Higher scores on the emotional representation subscale denote higher levels of emotional distress. Although four causal subscales are included in the IPQ-S, the items are not easily classified into meaningful dimensions and were not reported in the original paper by Lobban et al. (2004). For the same reasons they were also not used here.

Procedure

Participants were interviewed on two occasions, between 6 months to 24 months apart, at which times they were assisted by the interviewer in filling out the quality of life, Recovery Style, and Illness Perceptions questionnaires. If participants consented, their key workers were also asked to fill out the engagement, psychiatric symptom, and life skills measures.

Power Calculation

In relation to Hypothesis 1 (that recovery style at Time 1 would predict outcome at Time 2), the power calculation indicated that, in order to achieve 80% power in detecting the effect sizes found in the Thompson *et al* (2003) longitudinal study, this investigation would require a minimum sample size of 40.

Ethics

Ethical approval was sought and obtained from the relevant Trust's ethics committee (See Appendix 1). At both time points, after reading an information sheet, participants were asked for written consent to (1) take part in the study, (2) for their key-workers to fill out questionnaires regarding their care, and (3) for the researcher to be allowed to look at relevant sections of their medical notes. Participants were informed that they could withdraw, postpone, or interrupt the interview at any time and that their responses would be treated confidentially (See Appendix 2 & 4).

Results

Participant Characteristics

Of the original 50 people who took part at time 1, 26 agreed to take part again at time 2 and a further 5 gave consent for their key workers to fill out the staff questionnaires. 10 of the original sample declined to take part again, 6 either could not be located or had moved out of the area, and 3 had died in the interim period.

The sample included 10 women (32%) and 21 men (68%), a ratio that corresponds to the general incidence of diagnosis of schizophrenia. 90% (n=28) of the sample had received a diagnosis of schizophrenia while the remaining 10% (n=3) were diagnosed with schizo-affective disorder. The mean age of the sample was 40 years (SD=10.6), and mean duration of mental health problems was 18 years (Range 2-40 years, SD=12.1). The mean age of leaving education was 16.2 years (SD=2.4). At time 1, 75% (n=23) of participants were in high support accommodation (e.g. community accommodation with staff on site 24hrs a day) and 26% (n=8) were in in-patient units. At T2 this had changed to 55% (n=17) in high supported accommodation, 42% in low supported accommodation (e.g. own flat with support) and 3% (n=1) in inpatient accommodation. 42% (n=13) of the sample identified themselves as "White-British", 19.4% (n=6) as "Black British-Caribbean", and 13% (n=4) as "Black British-African". None of the demographic variables showed a significant relationship with any of the outcome variables and were therefore not entered into further analysis.

As a group, the individuals who dropped out of the study after time 1 did not differ significantly from those who were assessed again at time 2 in terms of demographics or recovery style. However, the dropouts were significantly less impaired on the LSP at time 1: t=2.65, (df=48, p=. 01).

Measures

Table 1 shows the mean item scores, standard deviations, and Cronbach's Alpha (split-half reliability statistic) of all measures for time 1 and time 2. Cronbach's Alpha provides a test of internal reliability; scales with an Alpha of below 0.60 were excluded from further analysis. The personal control subscale at time 1, and timeline cyclical and personal blame subscales at time 2 were therefore excluded from further analysis due to low internal reliability (alpha = .49, .59, .21, respectively).

Table 1. Descriptive statistics for all measures at time 1 and time 2

Scale name (no. measures collected at time 2)	Time 1		Time 2		Significant Change T1-T2	Significant Correlation T1-T2
	Mean Total (SD)	Cronbach's Alpha	Mean Total (SD)	Cronbach's Alpha		
RSQ (26)	20.52 (5.9)	.0765	23.54 (5.3)	.73	*	
BPRS (31)	60.6 (16)	.82	56.6 (21.6)	.91		
BES (31)	14.9 (4.8)	.81	15.9 (4.1)	.73		
LSP (31)	34.0 (14.7)	.86	34.8 (17)	.91		**
MANSA (26)	45.66 (11.0)	.80	48.0 (11)	.79		**
IPQ-timeline; chronic (All IPQ = 21)	18.7 (4.9)	.77	18.3 (6)	.88		*
IPQ-timeline; cyclical	10.8 (2.1)	.63	14.3 (3.2)	.59	**	
IPQ-consequence	37 (8)	.82	37.8 (8.9)	.84		**
IPQ-personal control	13.5 (2.5)	.49	14.0 (3.7)	.77		**
IPQ-personal blame	8.97 (2.8)	.70	9.7 (2.4)	.21		**
IPQ-treatment control	16.6 (4.1)	.76	17.6 (4.1)	.75		**
IPQ-Illness coherence	13.2 (3.4)	.596	13.5 (4.7)	.86		*
IPQ-emotional representation	32.0 (6)	.79	31.2 (8.4)	.89		*
IPQ-total symptoms	33.4 (12.1)	na	37.7 (16.3)	na		**
IPQ-prop. MH.	0.43 (0.3)	na	0.44 (0.3)	na		*
IPQ-prop. Meds	0.18 (0.2)	na	0.16 (0.1)	na		**
IPQ-prop Other	0.54 (0.3)	na	0.48 (0.3)	na		

All measures at time 1 n= 31. IPQ-prop. MH, Meds, & Other = proportion of symptoms attributed to mental health problems, side-effects of medication, or other factors, respectively. * p <.05, ** p<.01

Interestingly, the only variables to change significantly across the time period were recovery style and IPQ-cyclical. Aside from this, all other illness perceptions were remarkably stable, while ratings of symptom severity and engagement neither changed nor correlated between each time. The data was analysed in terms of Skewedness and Kurtosis and met parametric assumptions.

Analyses

It should be noted that, as the following section shows, because the hypothesized relationships between illness perceptions and recovery style (Hypothesis 2) and between recovery style and outcome (Hypothesis 3) were not found, mediational analysis was not pursued. In view of this, the analyses contained herein are of an exploratory nature.

Univariate Analysis

Time 1

Table 2 shows the results of univariate correlations between the independent and dependent variables at time 1. A more integrating recovery style was significantly associated with higher self-reported quality of life, less impairment, less severe symptoms, and perceptions of treatment being more effective. Illness perceptions did not show any relationship with impairment, but perceptions of worse consequences, greater emotional impact, and more reported symptoms were associated with poorer self-reported quality of life. Engagement was positively associated with a tendency to attribute symptoms to either mental illness or side-effects of medication, and negatively associated with a tendency to attribute symptoms to other factors.

Time 2

At time 2, recovery style did not correlate significantly with any of the outcome variables, or with illness perceptions (see Table 3). However, once again, perceptions of worse consequences of mental illness, greater emotional impact, and a higher reported number of symptoms were associated with poorer quality of life. Poorer engagement was again associated with a tendency to attribute one's symptoms to sources other than mental illness or side-effects of medication, while the association seen at time 1 between engagement and attributing symptoms to mental health problems seen, here approached significance.

Table 2. Cross sectional correlations at time 1 (all n = 31)

Independent variable	Quality of Life (MANSA) Pearson's r (p)	Impairment (LSP) Pearson's r (p)	Engagement (BES) Pearson's r (p)	Recovery Style (RSQ) Pearson's r (p)
Recovery Style (RSQ)	**.375 (.045)**	**-.456 (.01)**	.276 (.133)	na
Symptoms (BPRS)	**-.435 (.018)**	**.526 (.002)**	**0.2 (.028)**	**-.483 (.006)**
IPQ-timeline; chronic	-.298 (.124)	.076 (.689)	.326 (.079)	-.001 (.995)
IPQ-timeline; cyclical	-.050 (.80)	.002 (.993)	.214 (.257)	.127 (.504)
IPQ-consequence	**-.583 (.001)**	.081 (.672)	.125 (.510)	-.143 (.452)
IPQ-personal blame	-.020 (.918)	.050 (.792	-.026 (.893)	-.100 (.599)
IPQ-treatment control	.236 (.226)	-.244 (.194)	.065 (.732)	**.364 (.048)**
IPQ-emotional representation	**-.422 (.025)**	.120 (.528)	.073 (.703)	-.218 (.248)
IPQ-illness coherence	-.350 (.068)	.142 (.453)	-.130 (.493)	-.313 (.093)
IPQ-total number symptoms	**-.439 (.019)**	.057 (.763)	.177 (.351)	.050 (.792)
IPQ-prop. MH.	.155 (.432)	-.280 (.134)	**.425 (.019)**	.144 (.447)
IPQ-prop. Meds.	-.139 (.481)	.194 (.303)	**.438 (.015)**	.072 (.704)
IPQ-prop. Other	-.171 (.384)	.057 (.767)	**-.407 (.026)**	-.067 (.725)

Table 3. Cross sectional correlations at time 2

Independent variable	Quality of Life (MANSA) n = 26 Pearson's r (p)	Impairment (LSP) n = 31 Pearson's r (p)	Engagement (BES) n = 31 Pearson's r (p)	Recovery Style (RSQ) n = 26 Pearson's r (p)
Recovery Style (n = 26)	.130 (.528)	-.092 (.562)	.058 (.782)	Na
Symptoms (n = 31)	-.078 (.70)	**.568 (.001)**	-.338 (.67)	.125 (.553)
IPQ-timeline; chronic	-205 (.349)	.272 (.221)	-.217 (.332)	.271 (.210
(all IPQ scales, n = 21)				
IPQ-consequence	**-.581 (.004)**	-.208 (.353)	.356 (.103)	-.003 (.991)
IPQ-personal control	.204 (.351)	.187 (.406)	.199 (.375)	.312 (.147)
IPQ-treatment control	.329 (.125)	.289 (.193)	.089 (.760)	.385 (.069)
IPQ-emotional representation	**-.496 (.016)**	-.105 (.642)	.237 (.288)	-.147 (.503)
IPQ-illness coherence	-.231 (.289)	-.154 (.493)	.266 (.231)	-.257 (.236)
IPQ-total number symptoms	**-.501 (0.15)**	-.172 (.444)	-.015 (.9428	.069 (.753)
IPQ-prop. MH.	.027 (.903)	-.205 (.359)	.405 (.061)	.321 (.135)
IPQ-prop. Meds.	.034 (.978)	-.301 (.174)	.324 (.142)	.092 (.675)
IPQ-prop. Other	-.006 (.978)	.343 (.118)	**-.433 (.044)**	-.014 (.948)

Longitudinal

Table 4 shows the correlations between independent variables at time 1 and outcome variables at time 2. While recovery style at time 1 was not predictive of any of the outcome variables at time 2, the illness perceptions of worse consequences of mental illness, a stronger negative emotional impact, and a greater reported number of symptoms at time 1 were associated with poorer quality of life at time 2. However, given that these variables separately correlated at each time period, it is not possible to determine the direction of this relationship.

Table 4. Correlations between measures at time 1 and outcome variables at time 2

Independent variables at time 1	Quality of Life (MANSA) T2 Pearson's r (p)	Impairment (LSP) T2 Pearson's r (p)	Engagement (BES) T2 Pearson's r (p)	RSQ T2 Pearson's r (p)	RSQ change T2-T1 Pearson's r (p)
RSQ	.258 (.184)	-.063 (.740)	-.086 (.652)	.345 (.084)	**-.650 (.000)**
BPRS	-.056 (.775)	.188 (.319)	-.139 (.464)	-.082 (.691)	**.395 (.040)**
MANSA	**.791 (.000)**	.101 (.611)	-.200 (.307)	.046 (.826)	-.281 (.173)
LSP	.081 (.977)	**.535 (.002)**	-.278 (.136)	.090 (.602)	**.427 (.030)**
BES	-.046 (817)	-.167 (.378)	.291 (.118)	.151 (.461)	-.163 (.420)
IPQ-timeline; chronic	-.343 (.08)	-.035 (.86)	.24 (.202)	.27 (.21)	.165 (.422)
IPQ-timeline; cyclical	-.01 (.90)	-.192 (.319)	.204 (.287)	-.137 (.533)	-.100 (.625)
IPQ-consequence	**-.585 (.001)**	-.137 (.48)	**.398 (.032)**	-.003 (.99)	.146 (.478)
IPQ-personal control	.001 (.995)	.269 (.159	.093 (.631)	.327 (.103)	.073 (.722)
IPQ-personal blame	.196 (.326)	-.179 (.35)	**.393 (.035)**	.31 (.15)	.133 (517)
IPQ-treatment control	.226 (.256)	-.238 (.215)	-.171 (.376)	.39 (.069)	-.062 (.762)
IPQ-emotional representation	**-.524 (.005)**	-.071 (.713)	.341 (.07)	-.15 (.50)	.126 (.538)
IPQ- total no. symptoms	**-0.467 (.014)**	-.059 (.76)	,142 (.463)	.07 (.75)	.119 (563)
IPQ-prop. MH.	-.062 (.76)	.189 (.33)	-.322 (.089)	.32 (.14)	-.097 (.639)
IPQ-prop Meds.	.034 (.89)	-.301 (.17)	.324 (.142)	.085 (.679)	-.081 (.695)
IPQ-prop Other	-.062 (.76)	.189 (.327)	-.322 (.089)	.019 (.927)	.144 (.481)

Recovery style at time 2 was not associated with any of the variables at time 1. However, change in recovery style from time 1 to time 2 was positively associated with severity of symptoms and negatively associated with recovery style at time 1. That is, more severe symptoms, greater impairment, and being more sealing at time 1 was associated with a change toward a more integrating recovery style. Change in recovery style was also negatively associated with change in LSP scores (r=-.466, p=. 019), indicating that a shift toward a more integrating style tended to occur alongside a reduction in level of impairment.

Multivariate Analysis

Longitudinal data

A standard regression analysis was carried out to determine which variables were most predictive of change in recovery style. Impairment, recovery style, and symptom severity, all at time 1, and change in impairment between time 1 and time 2, were entered into the model. Using the enter method, the overall model showed a significant fit with the data ($F_{2, 20}$=4.937, p=. 006; see table 5), accounting for 39.6% of the variance in change in recovery style. The independent effect of RSQ scores at time 1 was significant (Standardized Beta=-.551, p=. 009).

Table 5. Predicting change in recovery style.

Model	Adjusted R-squared	R-squared	Significant F change	Standardized Beta	P value
BPRS	.396	.497	.006	-.039	.857
LSP				.124	.576
Change in LSP				-.208	.289
RSQ T1				-.551	.009

Cross-sectional

Standard regression analyses were carried out to examine which correlated variables predicted quality of life at each time period. Using the enter method, a significant model emerged at time 1 ($F_{5, 22}$=4.102, p=. 009) using severity of symptoms, recovery style, total number of reported symptoms, perceived consequences, and emotional impact. This model accounted for 36.5% of the variance in quality of life (Adjusted R square = .365; see Table 6). The independent effect of IPQ-consequences was significant (Standardized Beta=-2.245, p=. 035).

Table 6. Predicting quality of life at time 1 from independent variables at time 1.

Model	Adjusted R-squared	R-squared	Significant F change	Standardized Beta	P value
BPRS	.365	.482	.009	-.799	.433
RSQ				1.089	.288
IPQ-total symptoms				-.489	.630
IPQ-consequence				-2.245	.035
IPQ-emotional representation				.732	.472

A second standard regression analysis was carried out to predict quality of life at time 2. Here, variables entered into the model were total number of reported symptoms, perceived consequences, and emotional impact at time 2. This model was also significant ($F_{3,19}$=4.374, p=. 017). This time, the model accounted for 31.5% of the variance in quality of life at time 2. None of the variables independently showed significant relationships with quality of life, although IPQ-consequences approached significance.

Table 7. Predicting quality of life at time 2 from independent variables at time 2.

Model	Adjusted R-squared	R-squared	Significant F change	Standardized Beta	P value
IPQ-total symptoms	.315	.409	.017	-.383	.156
IPQ-consequence				-1.968	.064
IPQ-emotional representation				1.045	.309

Discussion

The findings of this study support the hypothesis that illness perceptions are related to perceived quality of life and offer tentative support that perceptions of treatment control may be related to recovery style. However, little evidence was found of the hypothesized relationship between illness perceptions and impairment or between recovery style and outcome. The overall findings do not support the notion that recovery style mediates the relationship between illness perceptions and outcome.

Recovery style and outcome

The results, in general, did not support the prediction that recovery style at time 1 would predict outcome at time 2. Recovery style did correlate with quality of life at time 1 but this relationship did not persist over time, with no association evident at time 2. This is in contrast to Thompson et al.'s (2003) study in which recovery style accounted for 12.4% of the variance in quality of life 12 months later. However, it is worth noting that this disparity may have arisen out of the use of different tools to assess QoL: the Quality of Life Scale (QLS; Heinrichs et al., 1984) used by Thompson et al. (2003), is an objective scale designed to assess deficit symptoms, whereas the MANSA is based on self report and tends not to focus on mental health symptoms. Objective and subjective measures of QoL have been shown to produce different results and the QLS has been criticised for measuring too narrow a range of factors related to QoL (Czernikiewicsz & Gorecka, 2003).

The relationship between impairment and recovery style appeared to follow a similar pattern, with an association at time 1 but not at time 2. Recovery style could not, however, independently account for a significant proportion of the variance in impairment at time 1. Furthermore, no evidence was found of a relationship between engagement and recovery style, contrary to that observed by Tait et al., 2003).

While static measurements of recovery style showed few associations, *change* in recovery style between the time points was related to several variables at time 1 and also to a change in level of impairment. Taken together, the direction of these relationships suggests that as individual's level of impairment changes so also does their recovery style. That is, an increase in impairment over time occurs alongside a move toward a more sealing style while a reduction in impairment over time corresponds with a move toward a more integrating style. This may support the notion that people seal over in order to protect themselves against the psychological impact of their condition (Drayton et al., 1998) or might alternatively suggest that as people become less impaired they also become more able to think about what has happened or is happening to them.

Illness perceptions and outcome

The findings in relation to illness perceptions broadly supported the hypothesis that beliefs about mental health problems at time 1 would be associated with outcome at time 2. However, not all beliefs were equally predictive. Perceptions of worse consequences, more emotional distress, and more symptoms emerged as the most stable predictors of quality of life across the measurement period, with perceptions of worse consequences emerging as a significant independent predictor. Additionally, the relationship between having a coherent understanding of ones mental health difficulties and quality of life at time 1 approached significance while correlations between the other illness perceptions (timeline, personal control, treatment control) and quality of life were non-significant but in the direction predicted, a result that may reflect the relatively low power of this study. These trends are in line those of Lobban et al. (2004), and suggest that the way one perceives one's mental health problems may be more important to satisfaction in other areas of life than the recovery style one adopts.

Contrary to the findings of Lobban et al. (2004), beliefs about mental health problems did not show any relationship with impairment. Such a finding is surprising given that one might expect, for example, that the more impaired one is, the greater one would perceive the consequences of one's mental health problems to be. The difference between these and Lobban et al.'s (2004) findings may be due to several reasons. Firstly, this could be due to a difference in the samples studied: whereas both groups are comparable in terms of diagnosis and age, their sample was recruited from Community Mental Health Teams and was therefore possibly a less disabled population. It may be that the more disabled a person is, particularly if this also means greater cognitive impairment, the less their views of their condition will be related to how impaired they are. Secondly, Lobban et al's sample was also significantly larger (N=124), and the present study may simply have lacked the power to detect the contribution of illness perceptions.

Illness perceptions also showed significant associations with engagement. Cross-sectionally, the strongest associations were with attributions of symptom causality while longitudinally perceptions of worse consequences or of greater personal blame predicted better engagement two years later. The findings in relation to symptom attribution may be unsurprising: if an individual does not think their symptoms arise from mental health problems or from side-effects of treatment, there may be less incentive to engage with mental health services. Similarly, it may be speculated that people who perceive worse consequences, or who feels they could do more to help themselves, may be more inclined to enlist help or assistance.

Illness perceptions and recovery style

The results did not support the prediction that illness perceptions at time 1 would be predictive of recovery style at time 2. The only illness perception that appeared to be related to recovery style was that of treatment control, which was significantly correlated at time 1 and approached significance at time 2. Thompson et al. (2003) have pointed out that integrators recovery style places them at a clinical advantage so it may be that their treatment actually is more effective. Alternatively, in line with Folkman and Lazarus' (1984) model of stress appraisal, if a person perceives the necessary resources to deal with a potential stressor (e.g. a mental health problem) are available, they may judge it to be less stressful and insurmountable and so feel more able to use an approach method of coping as opposed to an avoidant one.

Similarities with previous Studies

The findings of this study are mixed in relation to those of previous studies. Recovery style, or changes thereof, showed associations with quality of life, impairment, and severity of symptoms as seen in Thompson et al. (2003), albeit not of the same strength and persistence over time. In addition, recovery style changed over time confirming that it is not a stable personality characteristic (Tait et al., 2003,2004; Thompson et al, 2003). However, no association was found with engagement or with change in symptoms over time, in contrast to Tait et al., (2003).

The findings in terms of illness perceptions were similarly mixed. Illness perceptions were remarkably stable over time as Lobban et al. (2004) noted, and perceptions of worse consequences also emerged as the most powerful predictor of quality of life. However, perceptions relating to timeline or control did not show significant associations with quality of life and no correlations were found between any illness perceptions and impairment.

The differences between this and previous studies may arise from a number of sources. As noted above, the present sample was drawn from a population who tend to show a higher level of disability and more significant levels of residual symptoms, than those of prior studies in this area. Where impairment and symptoms exceed certain levels, it may be that other factors become less important in determining e.g. quality of life. The use of different measures may also explain some of the variation, also as discussed above, while the relatively small size of the sample may explain why some significant relationships observed elsewhere were not seen here.

Alternative explanations of the findings

As with any use of multiple comparisons where the accepted level of probability is not adjusted (i.e. retained at $p < .05$), there is an elevated chance of significant results arising out of sampling error or random variation (Type I errors). However, given that relationships persisted across the time period and are in keeping with predictions, this is less of a concern.

Clinical Implications

The overall findings of this study suggest that while symptoms are the strongest predictors of impairment, the way one thinks about one's condition and it's impact is more important in terms of quality of life and engagement. These findings support the use of integrated approaches to treatment and support that aim to control symptoms while also focusing on other areas of people's lives such as social and personal aspects. The importance of perceived consequences and emotional impact supports the movement away from deficit based models of care toward more strengths based approaches where the emphasis is on what people can do rather than what they cannot.

Limitations

The present research contains a number of limitations that must be borne in mind when interpreting the results. Several of these relate to power and sample size. Firstly, the initial power calculation suggested that to achieve acceptable power in determining the effects of recovery style, the sample size should be forty, whereas the actual number of responses was much lower than this due to drop out. Consequently, there is an elevated risk that real effects were not detected (Type II error) as well as a greater chance that observed findings may have arisen from random variation. Secondly, it is possible that those who were not followed up may have differed from those who were in a meaningful way thus introducing further bias to the sample. A third potential source of error relates to the number of comparisons done and the that many were unplanned, both of which increase the chance of obtaining a significant result by chance (Type I error).

A second limitation relates to the period under study. Due to the length of time between measurement points, events occurring during this time might have obscured relationships between the variables under study. For example previous research has suggested that individual's recovery style might vary as a function of distance from an acute episode (Tait et al., 2003). However, because relapses during the study period were not controlled for, their potential impact cannot be known. A related issue concerns inter-rater reliability between the time points. Because virtually all clients had moved on from the accommodation they were in at time 1, the staff report measures were almost without exception completed by different members of staff. While this is less problematic for measures such as the LSP where response options are clearly defined, measures such as the BPRS, where responses have subjective titles like "mild" or "severe", may be more problematic.

Lastly, this study is limited in terms of the types of illness beliefs assessed. For example, beliefs regarding causation were not included due to the difficulty in meaningfully coding them, while other scales were dropped from the analysis due to poor internal validity.

Future research questions

One of the main findings to emerge from this study is the relatively weak association between recovery style and outcome, in contrast to previous studies who have used less disabled populations. Various authors have argued for interventions to be tailored either to fit individuals' recovery style (e.g. McGlashan, 1987) or to encourage a move toward a more integrating style (e.g. Tait et al, 2003; Thompson et al., 2003). However, if there are people for whom other factors play a more significant role in outcome, then efforts might be more profitably employed elsewhere e.g. targeting illness perceptions. A relevant question for future research, therefore, may be to investigate whether the contribution of recovery style to outcome varies as a function of disability.

Secondly, given the importance of beliefs relating to consequences of mental health problems, a useful avenue for future research may be to investigate the determinants of such beliefs, or which perceived consequences in particular are the most important. In the introduction it was suggested that illness perceptions in general might be influenced by the effect of early experiences such as attachment status. Is this the case with consequence appraisals, or do current experiences such as stigma, social isolation, or treatment culture (e.g. deficit vs. strengths focus) play a greater role? Furthermore, as Lobban et al. (2003) point out, we still do not fully understand the relationship between illness beliefs and outcome. Consequently, intervention studies looking at whether changing beliefs leads to a reduction in distress or other improved outcomes are also to be welcomed.

References

Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: Towards an empirically validated stage model. Australian and New Zealand Journal of Psychiatry, 37, 586594.

Birchwood, M., Iqbal, Z., Chadwick, P., & Trower, P. (2000). Cognitive approach to depression and suicidal thinking in psychosis I. Ontogeny of post-psychotic depression. *British Journal of Psychiatry*, 177, 516-521.

Chadwick, P.D.J., Birchwood, M.J., & Trower, P. (1996). *Cognitive therapy for delusions,voices and paranoia*. Wiley.

Clifford P.I. (1998) M is for Outcome: The CORE Outcomes Initiative. *Journal of Mental Health*, 7 (1), 19-24.

Czernikiewicz, A. & Gorecka, J. (2003). A comparison of subjective and objective quality of life in a group of schizophrenic patients. *Psychiatry Poland,* 37(4), 669-8.

Diehl, S. (1995). The emotional stages of recovery. In C.Talley & S. Diehl (Eds.). *BRIDGES: A journey of hope, a peer education programme for consumers of mental health services*. Knoxville: Tennessee Alliance for the Mentally Ill.

Drayton, M. (1995) The emotional impact of schizophrenia. Clinical Psychology Forum, 82, 5-20.

Drayton, M., Birchwood, M., & Trower, P. (1998). Earl Attachment experience and recovery from Psychosis. *British Journal of Clinical Psychology*, 37, 269–284.

Hagger, M. & Orbell, S. (2003). A meta analytic review of the common-sense model of illness representations. *Psychology and Health, 18*, 141-184.

Iqbal, Z., Birchwood, M., Chadwick, P., & Trower, P. (2000). Cognitive approach to depression and suicidal thinking in psychosis II. Testing the validity of a social ranking model. *British Journal of Psychiatry*, 177, 522-528.

Jackson, H. J., McGorry, P. D., Edwards, J., Hulbert, C., Henry, L., Francey, S., Maude, D., Cocks, J., Power, P., Harrigan, S., & Dudgeon, P. (1998). Cognitively-orientated psychotherapy for early psychosis (COPE): Preliminary results. *British Journal of Psychiatry,* 172 (Suppl. 33), 93–100.

Jopson, N., & Moss-Morris, R. (2003). The role of illness severity and illness representations in adjusting to multiple sclerosis. *Journal of Psychosomatic Research*, 54 (6), 503–511.

Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representations and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *Handbook of psychology and health (Vol. 4).* Hillsdale, NJ: Lawrence Erlbaum Associates, Inc.

Lobban, F., Barrowclough, C., & Jones, S. (2005). Assessing Cognitive Representations of Mental Health Problems I. The Illness Perception questionnaire for schizophrenia. *British Journal of Clinical Psychology*, 44, 147-162.

Lobban, F., Barrowclough, C., & Jones, S. H. (2004). The impact of beliefs about mental health problems and coping on outcome in schizophrenia. *Psychological Medicine*, in press.

Luckoff, D., Liberman, R. P., & Nuechterlein, K. H. (1986). *Schizophrenia Bulletin*, 12, 578–593.

McGlashan, T. H. (1987). Recovery Style from Mental Illness and long term outcome. *Journal of Nervous and Mental Diseases*, 175, 681–685.

McGlashan, T. H., & Carpenter, W. (1981). Does attitude toward psychosis relate to outcome? *American Journal of Psychiatry*, 138, 797–801.

McGlashan, T. H., & Levy, S. (1977). Sealing over in a therapeutic community. *Psychiatry,* 40, 55–65.

McGlashan, T. H., Levy, S., & Carpenter, W. (1975). Integration and sealing over: Clinically distinct Recovery Styles from Schizophrenia. *Archives of General Psychiatry*, 32, 1269–1272.

Moss-Morris, R., & Chalder, T. (2003). Illness Perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. *Journal of Psychosomatic Research*, 55(4), 305–308.

Overall, J. E., & Gorham, D. R. (1962).The Brief Psychiatric Rating Scale. *Psychological Reports,* 10, 799–812.

Petrie, K.J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: longitudinal study. *British Medical Journal*, 312, 1191–1194.

Petrie, K. J., Cameron, L. D., Ellis, C. J., Buick, D., & Weinman, J. (2002). Changing Illness Perceptions after myocardial infarction: an early intervention randomized controlled trail. *Psychosomatic Medicine,* 64, 580–586.

Pettie, D., & Triolo, A. M. (1999). Illness as evolution: The search for identity and meaning in the recovery process. *Psychiatric Rehabilitation Journal, 22*(3), 255–263.

Priebe, S., Huxley, P. Knight, S., & Evans, S. (1999). Application and results of the Manchester short Assessment of quality of life (MANSA). *International Journal of Social Psychiatry*, 45 (1), 7–12.

Ralph, R. O., & The Recovery Advisory Group. (1999). The recovery advisory group recovery model. *National Conference on Mental Health Statistics.* http://www.mhsip.org/recovery/index.html

Rosen, A., Hadzi-Pavlovic, D., & Parker, G. (1989). The Life Skills Profile: A measure assessing function and disability in Schizophrenia. *Schizophrenia Bulleting*, 15 (2), 325–337.

Salmon, P. (2002). *The Psychology of Medicine and Surgury: A Guide for Psychologists, Counsellors, Nurses, and Doctors.* Chichester: Wiley.

Spaniol, L., Wewiorski, N.J., Gagne, C., & Anthony, W.A. (2002). The process of recovery from schizophrenia. *International Review of Psychiatry, 14*, 327-336.

Tait, L., Birchwood, M., & Trower, P. (2003). Predicting engagement with services for psychosis: insight, symptoms and Recovery Style. *British Journal of Psychiatry*, 182, 123–128.

Tait, L., Birchwood, M., & Trower P. (2004). Adapting to the challenge of psychosis: personal resilience and the use of sealing-over (avoiding) coping strategies. *British Journal of Psychiatry*, 185, 410–415.

Talley, S. (1999). *Self-regulation activities used by individuals with schizophrenia.* Dissertation Abstracts International: Section B: The Sciences and Engineering, 59 (12B), 6265. Univ. Microfilms International, US.

Thompson, K. N., McGorry, P. D., & Harrigan, S. M. (2003). Recovery Style and outcome in first-episode psychosis. *Schizophrenia Research*, 62, 31–36.

Ventura, J., Green, M. F., Shaner, A., & Liberman, R. P. (1993). Training and quality assurance in the use of the Expanded Brief Psychiatric Rating Scale: the 'drift busters'. *International Journal of Methods Psychiatric Research*, 3, 221–244.

Watson, P. and Garety, P. and Weinman, J. and Dunn, G. and Bebbington, P. and Fowler, D. and Freeman, D. and Kuipers, E. (2006) *Emotional dysfunction in schizophrenia spectrum psychosis: the role of illness perceptions.* Psychological Medicine, 36 (6). pp. 761-770.

Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire: A new method for assessing the cognitive representations of illness. *Psychology and Health*, 11, 114–129.

Wolfson, P., & Cupitt, C. (2001) Bexley Engagement Scale, in press.

Young, S. L., & Ensing, D. S. (1999). Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal, 22,* 219–231.

Part III

Critical Appraisal

Critical Appraisal

This research aimed to investigate possible determinants of recovery style, assumed to be a measure of psychological adjustment to schizophrenia. The study used the dataset from a previous trainee's research, repeating measurements at a second time point to create a longitudinal study. This section will describe aspects of the process including why this piece of research was chosen, it's potential limitations, and personal reflections.

Choosing the study

I had decided early on that I wanted to conduct my research in the area of psychosis. However, the research ideas I came up with were either a little too ambitious or were simply not feasible and it was suggested to me that an alternative would be to extend a previous trainee's research into recovery style and illness perceptions into a longitudinal study. This was an idea that appealed on several fronts. Having worked in the field of severe and enduring mental health for several years, in inpatient as well as community settings, I was struck by the mainly medical explanations for peoples responses to treatment and to their situation. These accounts seemed to lack sophistication and to deny the importance of the individual in their own lives, whereas the concepts of recovery style and illness perceptions were offered the possibility of a move toward a more psychological conceptualization of these issues. This also seemed a rare opportunity to undertake a longitudinal piece of work. Picking up where someone else had left off, furthermore meant that the sample was already found and ethical approval would probably be somewhat easier to obtain. Additionally, the original research happened to have been conducted in a service in which I had worked for several years and so I felt I was well placed to re-engage participants, but also attracted by the possibility of seeing them once again.

Recruiting participants and setting up interviews.

Following UCL and NHS ethics committee approval, the next step was to try to locate where participants were. I had thought this would be relatively straightforward for two reasons: firstly I suspected many would not have moved on since time 1 and, if they had, there would be records of where they'd gone; and secondly, I had links with the specialist local accommodation team responsible for movement around the rehabilitation system and felt I could use them as an extra resource to track remaining people down. However, as it turned out, practically every participant had moved since time 1 and neither individual units nor the local accommodation team seemed to have accurate records of where they had moved to. Only through a mixture of chasing countless dead leads, persistently ringing units, and randomly stumbling across people, did I manage to locate the bulk of the sample. Ironically, only when it was too late did I find out that there was a local computer system with, among other information, records of all client current locations, although I am unsure if I would have been granted permission to access this system. In hindsight, a solution would perhaps have been to include a list of participants when I initially contacted the managers of each unit, asking them to let me know which people they had living there.

Once I had found out where most of the participants were, the next stage was to find out if they would be willing to take part again. It was interesting to see how differently the units handled this, and seemed to say a lot about the philosophy at each location: Some just got a client onto the phone or asked me when I wanted to come and see them, while at the other extreme were managers who wanted written information about the research, including ethical approval, whereupon I was allowed to formally write to clients requesting a meeting. Unsurprisingly, there was also a lot of variation in how helpful individual staff were. Some told me they would ask their clients but then never got back to me while others persisted and tried repeatedly to engage people who were initially wary of being interviewed again.

This phase of the research raised several dilemmas. For example, if staff spoke to clients about taking part in the research, it saved me time and effort that I could use elsewhere. But, would they "sell" the research as well as I would? Alternatively, going back to people who'd declined to take part to see if they'd change their mind meant I might increase the size of the sample, but was this ethically sound?

Collecting the data

The variability between locations continued to the interviews themselves, with some units being more accommodating and helpful than others. However, the most striking aspect of this phase for me was the way participants responded to the questionnaires. I had expected people to find the interview challenging and emotional, mainly because I felt it covered generally negative things (e.g. loss, impairment, "illness"). However, when I asked for feedback at the end of the interview, most people seemed to have enjoyed the process. In fact, whereas I thought participants would just want it over with and be paid, it was I who often had to cut discussions short in order to keep the interview to a reasonable length. People seemed more than willing to talk about their experiences – from their point of view and in their language – to someone who was interested. I also had some alarming conversations with two clients about what schizophrenia was or was not supposed to be. In one of these instances, a client's diagnosis had been changed to "schizoaffective disorder" but he hadn't understood why and had resisted this. Interestingly, following our discussion about the supposed difference between the two diagnostic terms, he changed his mind. Elsewhere, participants seemed to appreciate candour around issues of relevance to them such as the inexactness of diagnosing, problems with use of terms such as "illness", and the pro's and con's of using or not using medication. All of this left me wondering how much opportunity people had to talk about their experiences or to ask questions at other times and how flexible the response of services was. After all, wasn't this one of the roles of staff and keyworkers (particularly in a service where, when I mentioned "recovery", so many claimed to be working within a "recovery model")? I wondered if staff usually were too busy to talk or if they lacked the confidence or knowledge to answer questions. Several years previously, when I had worked in this same service, many staff had resisted an initiative to assess clients with the MANSA due to an item in it that asks about their sex lives. On that occasion, many had felt such questions would be detrimental to clients; now I wondered if this might also reflect a more general underlying fear of the consequence of discussing clients' lives with them. All of this made me wonder how far the concept of recovery style could be stretched, and whether services or staff themselves could be classified as tending toward either "sealing" or "integrating".

Emerging doubts

In a design such as this, issues of importance include the following: that the sample are representative of the population they are drawn from (external validity); that findings reflect actual differences not random variation among the sample (internal validity); and that the instruments used accurately measure the construct under study (validity) and do this repeatedly (reliability). However, as the research progressed, a number of doubts regarding each of these issues began to emerge.

Sample

A general rule of thumb is that the larger the sample size, the more visible the variance in the dependent variables accounted for by the independent variables will be against the background of variance attributable to other factors, including measurement error and errors in sampling (Barker, Pistrang, & Elliot, 2002). The fact that the sample size did not meet that suggested by the power calculation was therefore a major source of concern, meaning that the study was less likely to find evidence of real relationships and more likely to be contaminated by the effects of factors not under study. Also, because the power calculation was conducted using the effect size from a study of a less disabled sample, it was possible that it was an underestimate anyway.

One potential source of 'noise' in relation to the sample related to co-morbidity. Aside from a primary diagnosis of a schizophrenia spectrum disorder, several participants appeared to meet the criteria for other major diagnoses, most significantly personality disorder and learning difficulties, and there were at least two people for whom I felt these were actually their most prominent issues. It is possible, of course, that this actually made the sample more representative of the target population. However, these features may also have affected the findings in ways that were not controlled for. For example, McGlashan (1987) has shown that recovery style and it's relation to outcome varies across diagnoses; individual's with Borderline Personality Disorder tended to be more integrating, and their recovery style was more predictive of outcome, than those with a diagnosis of schizophrenia. Intelligence and executive function also seem to affect recovery style, with higher IQ and better executive functioning being associated with integrating (Bell & Zito, 2005), as well as affecting the likelihood of questionnaire items being misunderstood. In response to this latter point, when I suspected participants might be having trouble, I tested this out by asking them if they knew what the question had meant before offering further explanations. Clearly this is not a failsafe method though, and I may have missed some individual's while not explaining sufficiently for others.

A second potential area of noise in the data may have arisen due to differences in symptoms. My experience in interviewing participants was that they differed substantially in terms of the kinds of symptoms they showed during testing and how severe they were, for example some people appearing quite suspicious; others showing apparent cognitive disorganization. Such differences were not reflected in the analysis, in which only a measure of overall symptom severity was entered, and so important variations due to different symptom types may have been missed. These observations also contributed to doubts regarding the study of "schizophrenia" and these will be elaborated below.

Measures

The measures used in this study were generally well validated and widely used. Nevertheless, it is important to note almost all staff questionnaires were filled out by different members of staff. That is, within each time point almost every participant' s symptom severity, level of engagement, and impairment was rated by a different member of staff and no client was rated by the same member of staff across the time points. Consequently, some of the variation - both cross-sectionally and longitudinally - may have resulted from differences in the way staff understood and rated these scales, rather than from actual variation among the clients. Perhaps the best example of this is the BPRS, which has been said to have excellent inter-rater reliability (Hedlund & Vieweg, 1980). However, to obtain such good reliability, Van Riesen and Vrijmoed-De (2000) suggest that rater training is "absolutely necessary", something that was not done in this study. In addition, most of the raters at time 1 were trained psychiatric nurses, while those at time 2 were mainly support workers, a difference that may have systematically affected how the raters understood the different symptoms in the BPRS and how severe they rated them.

Is it worth studying "Schizophrenia" at all?

In addition to concerns relating to the methodology used, as the research progressed I also began to question the validity of the constructs under study, in particular whether schizophrenia represented a valid category. As mentioned above, an important issue is whether the sample is representative of the population it is drawn from i.e. those with a diagnosis of schizophrenia. But what if we cannot be sure that people with a diagnosis of schizophrenia all have the same difficulties? Who then would the sample represent, and how would we know if observed effects were due to the variables under study rather than due to differences in problem type?

In fact many researchers have questioned the reliability and validity of "schizophrenia" in classifying people's distress (e.g. Bentall, 1990; Boyle, 1990). Historically, clinicians have not been very good at agreeing who should and who should not be included within the category of schizophrenia, something which has led to multiple re-definitions in an attempt to rectify this (Read 2004). The issue is further complicated because the current definition of schizophrenia is disjunctive; that is two people can have different symptom profiles but still receive the same diagnosis. There are actually 15 different ways two people can have completely different symptoms yet receive the same descriptive term of "schizophrenia" (Read, 2004), leading some to suggest that such a means of classification is "logically too primitive for scientific use" (Bannister, 1968).

Aside from problems in agreeing who can and who cannot be classified as having schizophrenia, a further difficulty concerns how valid the construct is at all. If schizophrenia is an actual "thing", one might expect it to have a unique symptom cluster not seen in other disorders, an identifiable aetiology, and a predictable outcome. Yet, in a review, Bentall and colleagues (1988) concluded that the construct of schizophrenia did not meet these criteria. These criticisms therefore not only challenge how confident I can be that the participants in my study belong to the group 'people with schizophrenia', but also whether this group reflects anything meaningful anyway. One way around these concerns may have been to group people on the basis of symptoms rather than diagnosis. Although, in theory, the BPRS could have been used to do this, this would not have been practical here due to the low numbers and the doubts regarding how reliable it's use was. However, future research should aim to either group on the basis of symptoms or to include different symptom types and their severity as separate variables in the analysis rather than a single global measure.

Personal reflection

So, looking back, what are my feelings about the whole process? Certainly there have been some disappointments. Initially I had high hopes, fantasies even, of completing a piece of research that would add something significant to the scientific knowledge base; that I would find clear evidence of relationships. Looking back, such hopes seem almost grandiose. Of course, in research, finding no evidence for a relationship can be just as important as finding evidence, but most people, including me (and journals, it would seem) want to see "effects". So, I was disappointed not to confirm my main hypotheses, even in the context of the doubts outlined above.

On the other hand, there have also been successes. At the beginning I stood at the bottom of the mountain that was the thesis, wondering how or if I would get to the top. The process has taught me, however, that by breaking it down, setting targets, and working steadily, such a task is possible and need not be a major source of stress: I feel more able to tackle big tasks in the future. The journey has also necessitated the development of skills such as planning, time and resource management, assimilation of divergent ideas, and critical data analysis – all of which will be useful in years to come. The most fulfilling aspects, though, involved the participants. Conducting the research gave me the opportunity simply to ask questions about things that interested me, something that held particular meaning because I'd known many of the participants previously. Change within rehabilitation services can also be slow and sometimes hard to notice. Thus, it was also immensely rewarding to be able to see how, three years after I'd last seen them, most of the participants had moved on to become more independent and in control of their lives.

The work has also greatly influenced my thinking about the (sometimes tenuous) relationship between the strongly held ideas we can have and the actual evidence in support of those ideas. Examples include how often we talk about issues of causation with our clients and to each other, yet how hard it actually is to prove such a relationship; how, often findings of single studies are used to support opinions, yet how seldom replication studies are carried out to confirm those findings; or how easy it is to get excited by statistically significant results but to lose sight of what 'real life' significance they actually have.

Closing comments

Planning, conducting, and writing up this research has represented a journey thats had its definite highs and lows. Until this, I had held on to a rather naïve idea of what research (and me as a researcher) could achieve, and the process proved to be a rude awakening from that particular fantasy. On the other hand, this has given me a more realistic idea of research can be useful and has enhanced my understanding of the limits of our knowledge and of the evidence we use to support it. I have also been amused by the research 'game' where the researcher 'butter's up' participants and lies about how long interviews will take, while the participants fib a little about how quickly they will return questionnaires (if at all!), or the delicate balance between being ultra nice to the staff whose cooperation is so needed with a more cajoling, badgering approach when people are slow to get back. Finally, I have puzzled over the contrast between the research and practical aspects of training, which have sometimes felt like uncomfortable bedfellows: one with a critical, doubting stance, the other confident, assuming, and at times seeming to show a degree of arrogance. These two aspects have seemed to reflect something of a paradoxical heart to clinical psychology that I had not previously seen, where one is supposed to simultaneously be a sceptic but also a believer. Difficulty in resolving this may be a part of the reason why so few clinical psychologists continue with research after training.

References

Bannister, D. (1968). The logical requirements for research into schizophrenia. *British Journal of Psychiatry,* 114. 181-8.

Bell, M.D. & Zito, W. (2005). Integrated Versus Sealed-Over Recovery in Schizophrenia: BORRTI and Executive Function. *Journal of Nervous and Mental Disease,* 193(1). 3-8.

Bentall, R. (1990). The syndromes and symptoms of psychosis. In R Bentall (Ed.). *Reconstructing Schizophrenia.* London: Routledge

Bentall, R., Jackson, H. & Pilgrim, D. (1988). Abandoning the concept of schizophrenia: Some implications of validity arguments for psychological research into psychotic phenomena. *British Journal of Clinical Psychology,* 27, 303-324.

Boyle, M. (1990). *Schizophrenia: A Scientific Delusion?* London, New York: Routledge.

Hedlund, J.L. & Vieweg, B.W. (1980). The brief psychiatric rating scale (BPRS): A comprehensive review. Journal of Operational Psychiatry, 11, 48– 65.

McGlashan, T. H. (1987). Recovery Style from Mental Illness and long-term outcome. *Journal of Nervous and Mental Diseases*, 175, 681–685.

Read, J. (2004). Does 'schizophrenia' exist?. In J. Read, L. Mosher, & R. Bentall (Eds.). *Models of madness: psychological, social, and biological approaches to schizophrenia.* Hove & New York: Brunner-Routledge

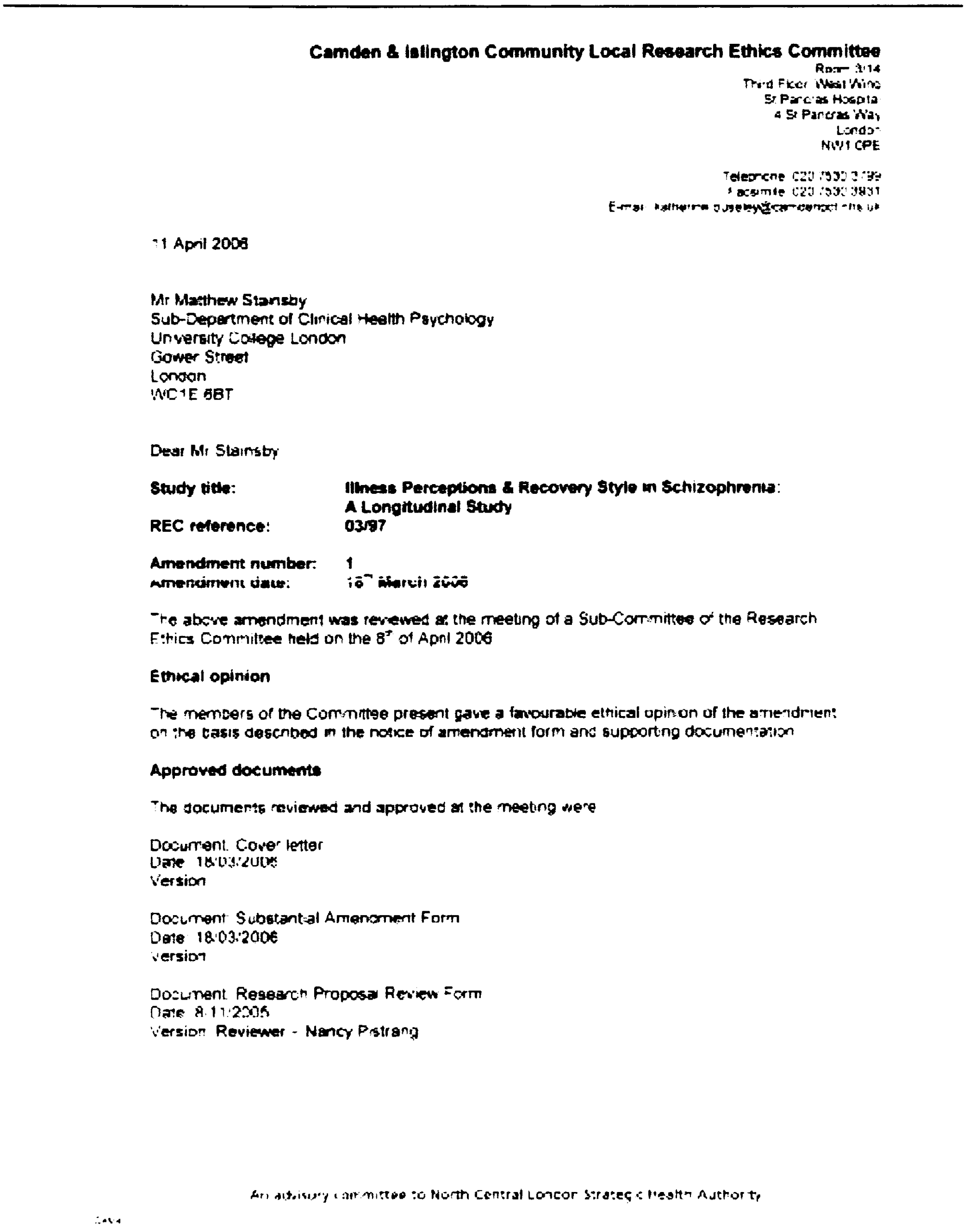
Van Riesen, H. & Vrijmoed-De, M.C. (2000). Rating Scales for Psychoneuropharmacology (CD-ROM). Elsevier Science.

Part IV

Appendices

Appendix 1

Letter of ethical approval



Camden & Islington Community Local Research Ethics Committee
Room 3/14
Third Floor West Wing
St Pancras Hospital
4 St Pancras Way
London
NW1 0PE

Telephone: 020 7530 3799
Facsimile: 020 7530 3931
E-mail: [illegible]

11 April 2006

Mr Matthew Stainsby
Sub-Department of Clinical Health Psychology
University College London
Gower Street
London
WC1E 6BT

Dear Mr Stainsby

Study title: **Illness Perceptions & Recovery Style in Schizophrenia: A Longitudinal Study**
REC reference: **03/97**

Amendment number: 1
Amendment date: 18th March 2006

The above amendment was reviewed at the meeting of a Sub-Committee of the Research Ethics Committee held on the 8th of April 2006

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation

Approved documents

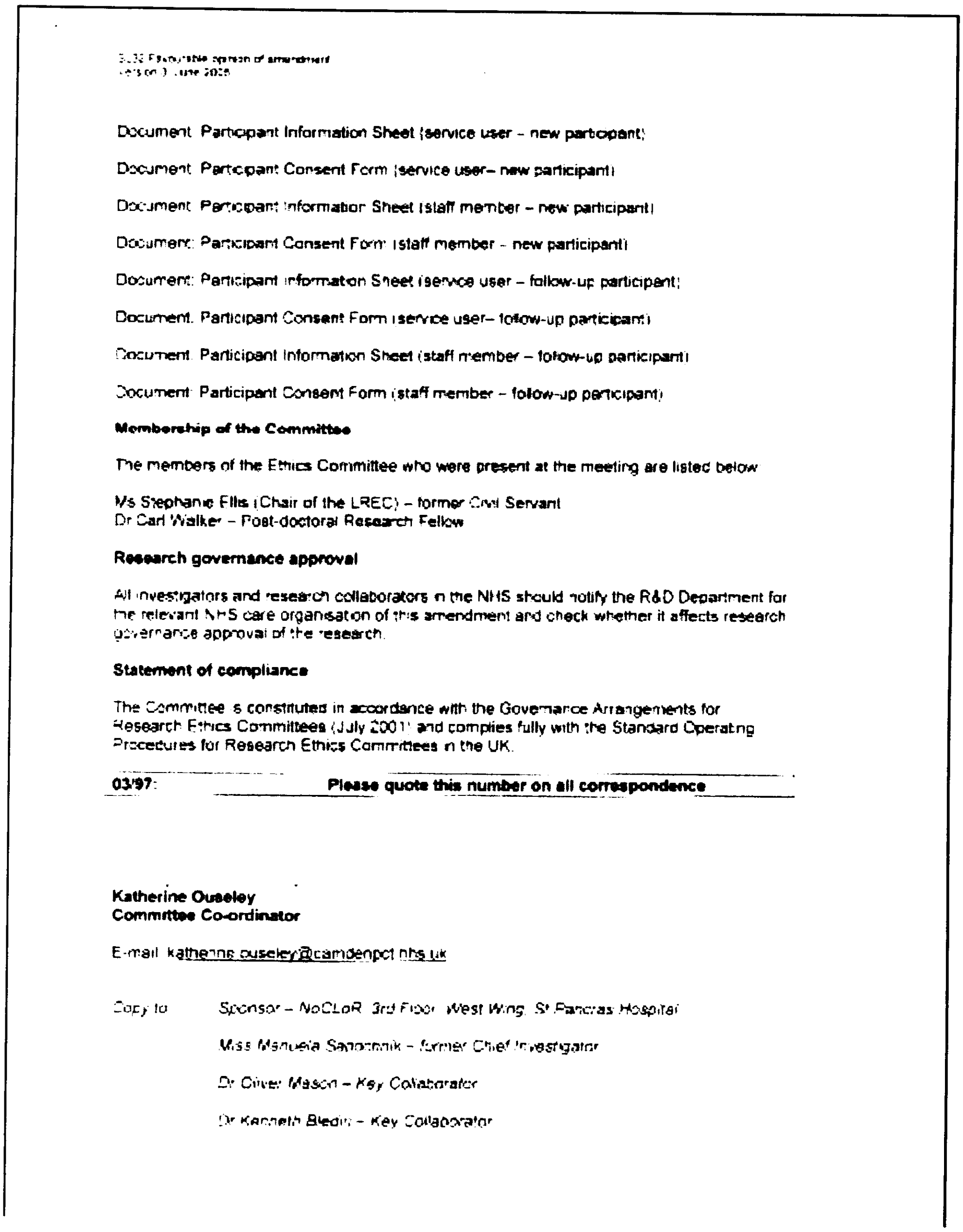
The documents reviewed and approved at the meeting were

Document: Cover letter
Date: 18/03/2006
Version:

Document: Substantial Amendment Form
Date: 18/03/2006
Version:

Document: Research Proposal Review Form
Date: 8/11/2005
Version: Reviewer - Nancy Pistrang

An advisory committee to North Central London Strategic Health Authority



SL32 Favourable opinion of amendment
Version 3, June 2005

Document Participant Information Sheet (service user – new participant)

Document Participant Consent Form (service user– new participant)

Document Participant Information Sheet (staff member – new participant)

Document: Participant Consent Form (staff member – new participant)

Document: Participant information Sheet (service user – follow-up participant)

Document. Participant Consent Form (service user– follow-up participant)

Document. Participant Information Sheet (staff member – follow-up participant)

Document Participant Consent Form (staff member – follow-up participant)

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed below

Ms Stephanie Ellis (Chair of the LREC) – former Civil Servant
Dr Carl Walker – Post-doctoral Research Fellow

Research governance approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

03/97: **Please quote this number on all correspondence**

Katherine Ouseley
Committee Co-ordinator

E-mail katherine.ouseley@camdenpct.nhs.uk

Copy to *Sponsor – NoCLoR, 3rd Floor, West Wing, St Pancras Hospital*

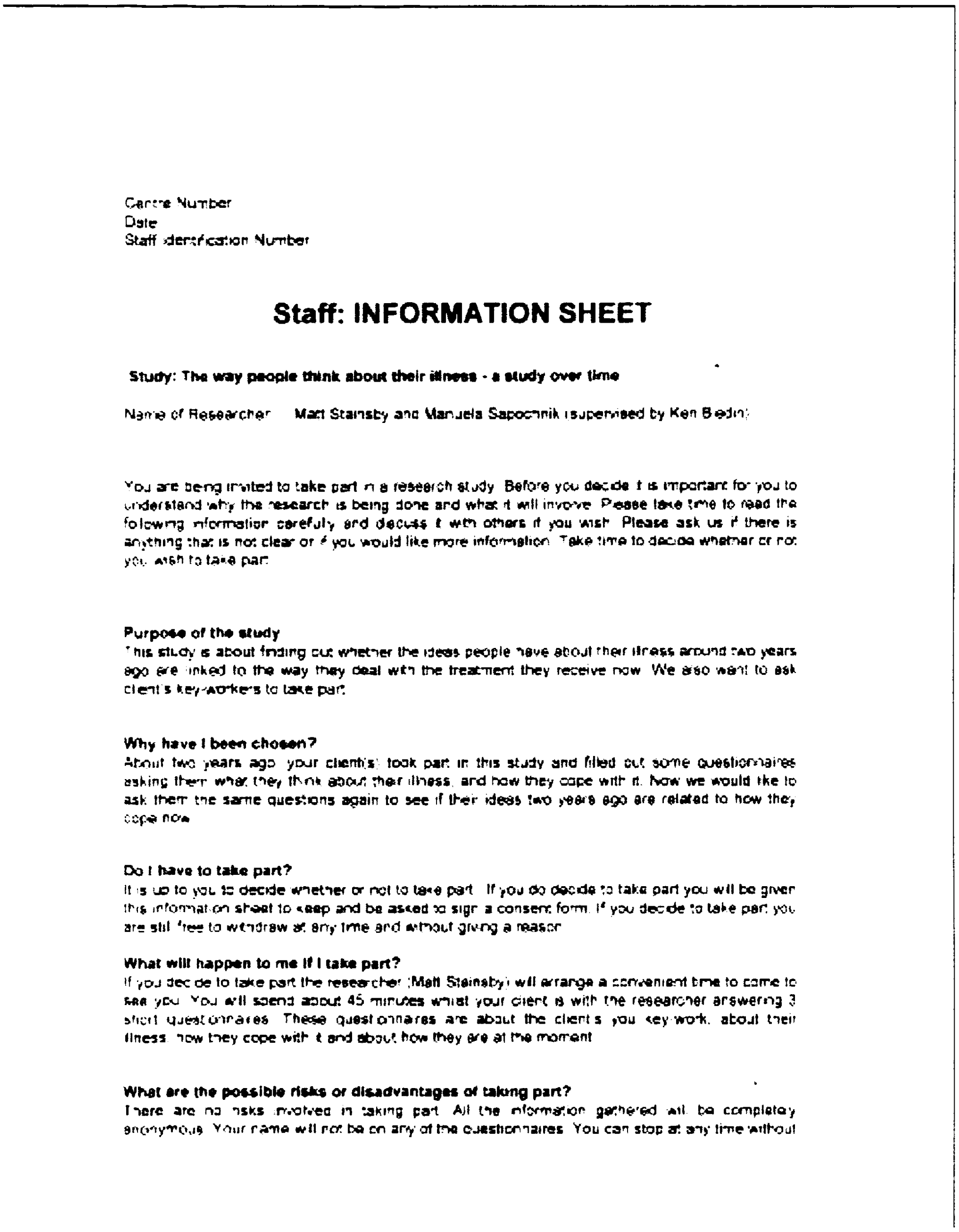
Miss Manuela Sanotnik – former Chief Investigator

Dr Oliver Mason – Key Collaborator

Dr Kenneth Bledin – Key Collaborator

Appendix 2

Participant Information Sheet



Centre Number
Date
Staff Identification Number

Staff: INFORMATION SHEET

Study: The way people think about their illness - a study over time

Name of Researcher: Matt Stainsby and Manuela Sapochnik (supervised by Ken Bledin)

You are being invited to take part in a research study. Before you decide 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 others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

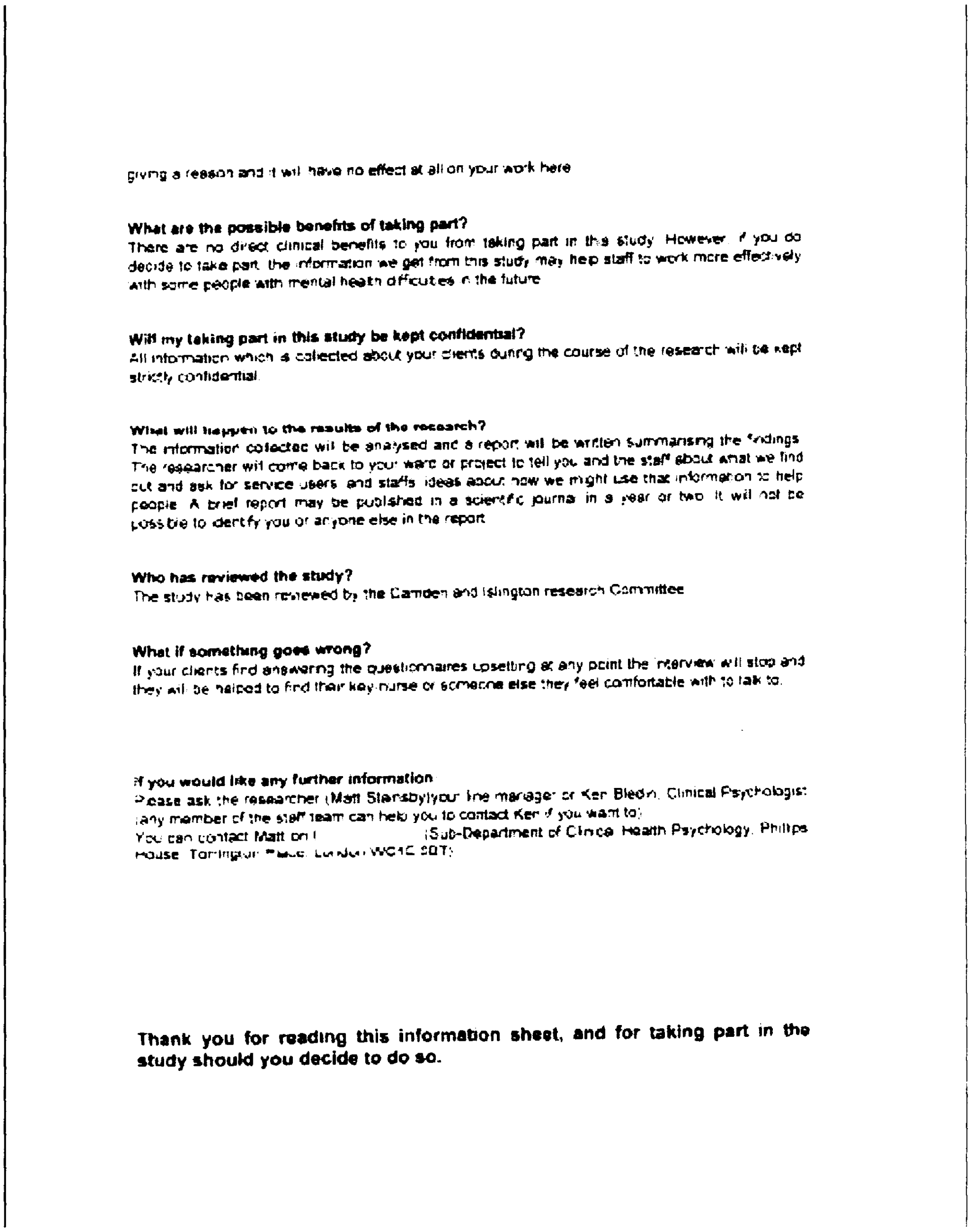
Purpose of the study
This study is about finding out whether the ideas people have about their illness around two years ago are linked to the way they deal with the treatment they receive now. We also want to ask client's key-workers to take part.

Why have I been chosen?
About two years ago, your client(s) took part in this study and filled out some questionnaires asking them what they think about their illness, and how they cope with it. Now we would like to ask them the same questions again to see if their ideas two years ago are related to how they cope now.

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 sheet to keep and 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.

What will happen to me if I take part?
If you decide to take part the researcher (Matt Stainsby) will arrange a convenient time to come to see you. You will spend about 45 minutes whilst your client is with the researcher answering 3 short questionnaires. These questionnaires are about the client's you key-work, about their illness, how they cope with it and about how they are at the moment.

What are the possible risks or disadvantages of taking part?
There are no risks involved in taking part. All the information gathered will be completely anonymous. Your name will not be on any of the questionnaires. You can stop at any time without



giving a reason and it will have no effect at all on your work here

What are the possible benefits of taking part?
There are no direct clinical benefits to you from taking part in this study. However, if you do decide to take part, the information we get from this study may help staff to work more effectively with some people with mental health difficulties in the future

Will my taking part in this study be kept confidential?
All information which is collected about your clients during the course of the research will be kept strictly confidential.

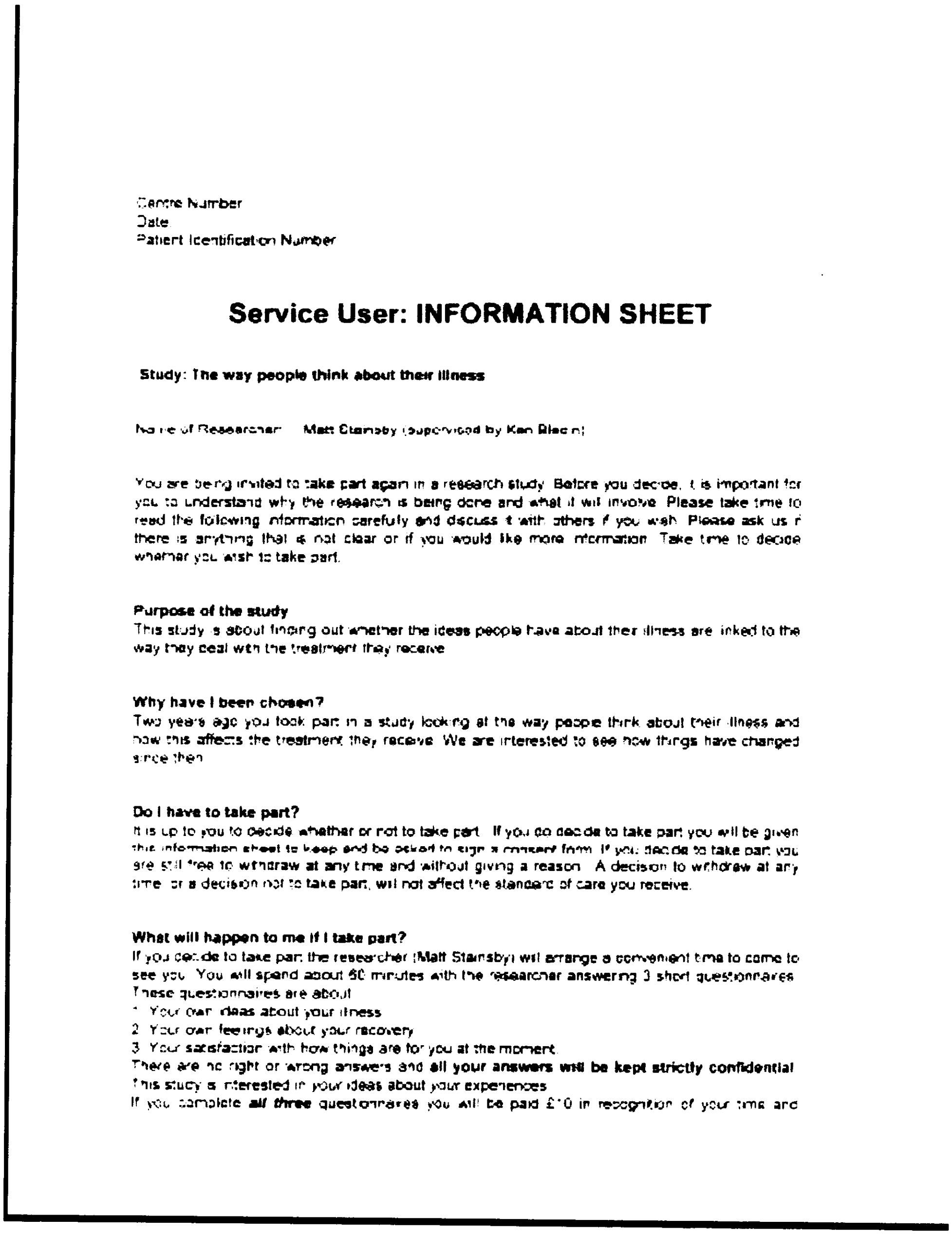
What will happen to the results of the research?
The information collected will be analysed and a report will be written summarising the findings. The researcher will come back to your ward or project to tell you and the staff about what we find out and ask for service users' and staffs' ideas about how we might use that information to help people. A brief report may be published in a scientific journal in a year or two. It will not be possible to identify you or anyone else in the report.

Who has reviewed the study?
The study has been reviewed by the Camden and Islington research Committee

What if something goes wrong?
If your clients find answering the questionnaires upsetting at any point the interview will stop and they will be helped to find their key-nurse or someone else they feel comfortable with to talk to.

If you would like any further information
Please ask the researcher (Matt Stansby)your line manager or Ken Bledin, Clinical Psychologist (any member of the staff team can help you to contact Ken if you want to).
You can contact Matt on (Sub-Department of Clinical Health Psychology, Philips House, Torrington Place, London WC1E 6BT)

Thank you for reading this information sheet, and for taking part in the study should you decide to do so.



Centre Number
Date
Patient Identification Number

Service User: INFORMATION SHEET

Study: The way people think about their illness

Name of Researcher **Matt Stainsby (supervised by Ken Blac n)**

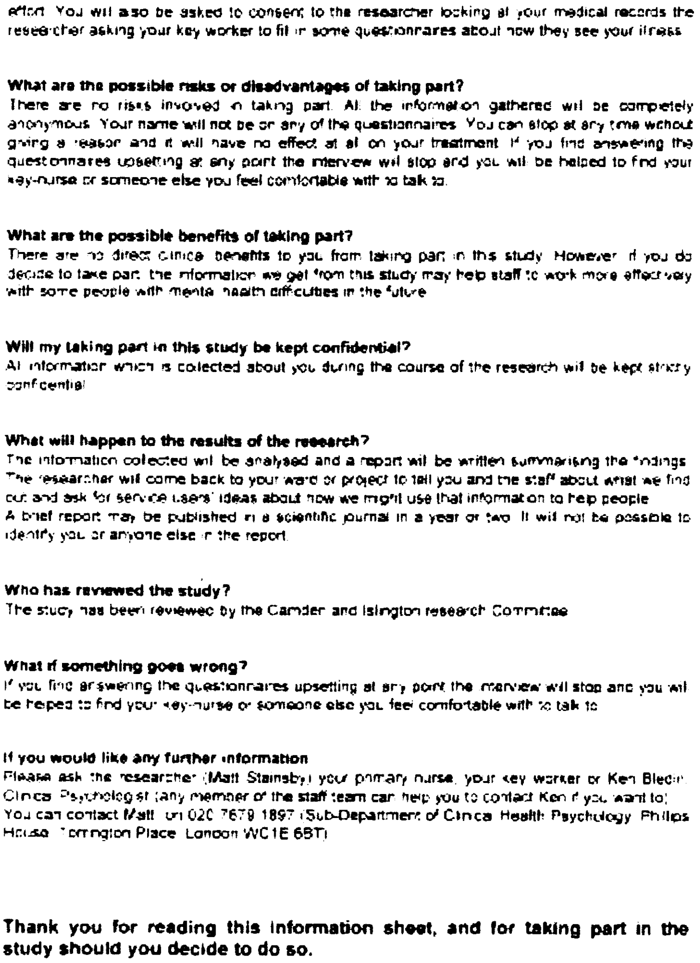
You are being invited to take part again in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is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

Purpose of the study
This study is about finding out whether the ideas people have about their illness are linked to the way they deal with the treatment they receive

Why have I been chosen?
Two years ago you took part in a study looking at the way people think about their illness and how this affects the treatment they receive. We are interested to see how things have changed since then

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 sheet to keep and 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. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
If you decide to take part the researcher (Matt Stainsby) will arrange a convenient time to come to see you. You will spend about 60 minutes with the researcher answering 3 short questionnaires.
These questionnaires are about
1 Your own ideas about your illness
2 Your own feelings about your recovery
3 Your satisfaction with how things are for you at the moment.
There are no right or wrong answers and **all your answers will be kept strictly confidential**
This study is interested in your ideas about your experiences
If you complete ***all three*** questionnaires you will be paid £10 in recognition of your time and



effort. You will also be asked to consent to the researcher looking at your medical records the researcher asking your key worker to fill in some questionnaires about how they see your illness.

What are the possible risks or disadvantages of taking part?
There are no risks involved in taking part. All the information gathered will be completely anonymous. Your name will not be on any of the questionnaires. You can stop at any time without giving a reason and it will have no effect at all on your treatment. If you find answering the questionnaires upsetting at any point the interview will stop and you will be helped to find your key-nurse or someone else you feel comfortable with to talk to.

What are the possible benefits of taking part?
There are no direct clinical benefits to you from taking part in this study. However, if you do decide to take part the information we get from this study may help staff to work more effectively with some people with mental health difficulties in the future.

Will my taking part in this study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential.

What will happen to the results of the research?
The information collected will be analysed and a report will be written summarising the findings. The researcher will come back to your ward or project to tell you and the staff about what we find out and ask for service users' ideas about how we might use that information to help people.
A brief report may be published in a scientific journal in a year or two. It will not be possible to identify you or anyone else in the report.

Who has reviewed the study?
The study has been reviewed by the Camden and Islington research Committee.

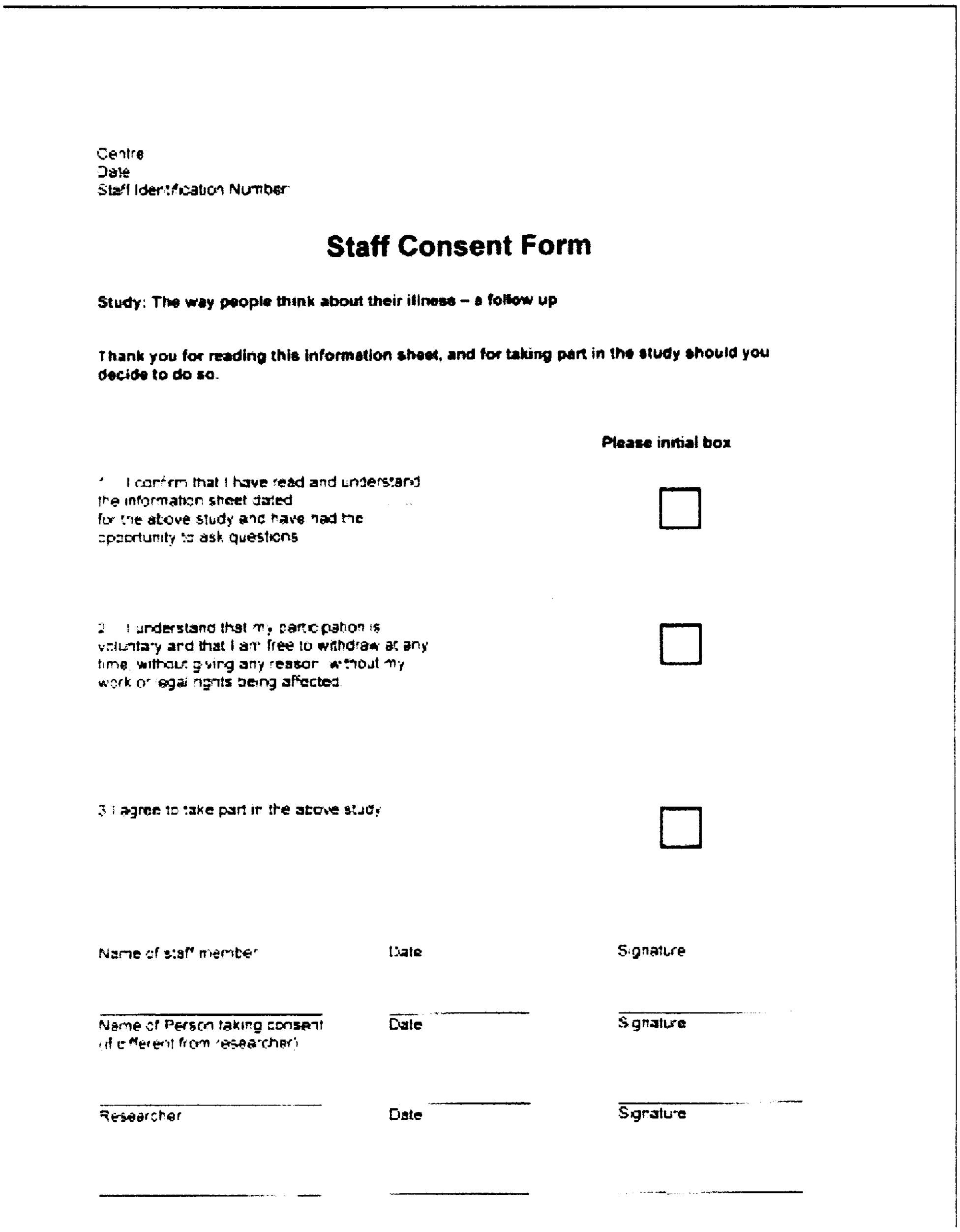
What if something goes wrong?
If you find answering the questionnaires upsetting at any point the interview will stop and you will be helped to find your key-nurse or someone else you feel comfortable with to talk to.

If you would like any further information
Please ask the researcher (Matt Stainsby), your primary nurse, your key worker or Ken Bledin, Clinical Psychologist (any member of the staff team can help you to contact Ken if you want to).
You can contact Matt on 020 7679 1897 (Sub-Department of Clinical Health Psychology, Philips House, Torrington Place, London WC1E 6BT).

Thank you for reading this information sheet, and for taking part in the study should you decide to do so.

Appendix 3

Participant Consent Forms



Centre
Date
Staff Identification Number

Staff Consent Form

Study: The way people think about their illness – a follow up

Thank you for reading this information sheet, and for taking part in the study should you decide to do so.

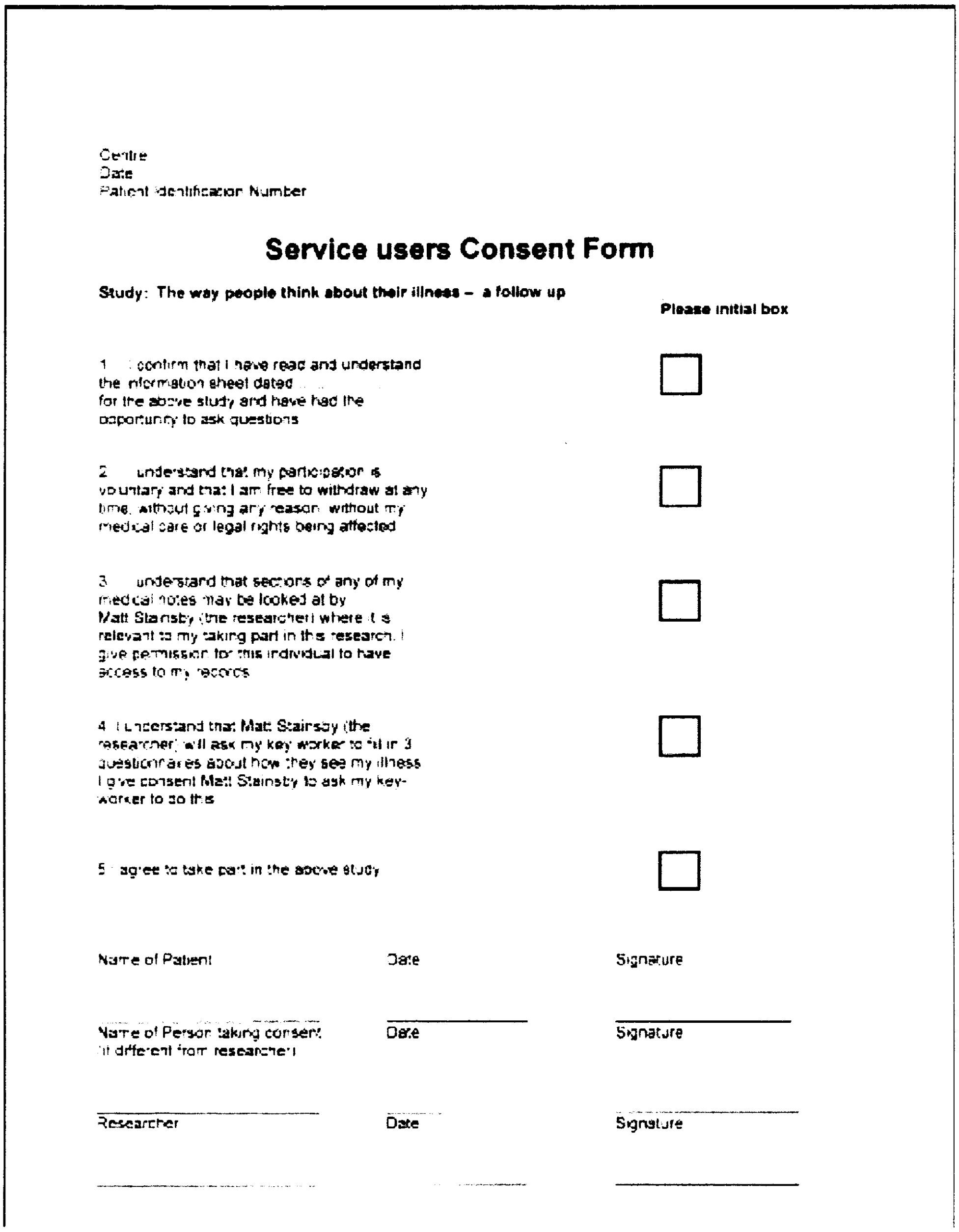
Please initial box

1 I confirm that I have read and understand the information sheet dated 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, without my work or legal rights being affected. ☐

3 I agree to take part in the above study ☐

Name of staff member	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature



Centre
Date
Patient Identification Number

Service users Consent Form

Study: The way people think about their illness – a follow up

Please initial box

1 I confirm that I have read and understand the information sheet dated ... 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, without my medical care or legal rights being affected ☐

3 I understand that sections of any of my medical notes may be looked at by Matt Stainsby (the researcher) where it is relevant to my taking part in this research. I give permission for this individual to have access to my records ☐

4 I understand that Matt Stainsby (the researcher) will ask my key worker to fill in 3 questionnaires about how they see my illness. I give consent Matt Stainsby to ask my key-worker to do this ☐

5 I agree to take part in the above study ☐

Name of Patient	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Appendix 4

Service-user Questionnaires

4.1 Manchester Short Assessment of Quality of Life

Participant Code:

Date:

This is a short questionnaire about how satisfied you are right now with different areas of your life. The first 2 sections are for information gathering and the last section is asks how happy you are with how things are at the moment.

Please answer all the questions.

Section 1

Date of Birth	
Gender	
Ethnic Origin	
Diagnosis	

Section 2

1. Age at leaving full time education?	
2. Employment status?	
3. What is your occupation?	
4. How many hours a week do you work?	
5. What is your total monthly income after tax?	
6. Which if any state benefits do you receive?	
7. How many children (if any) do you have?	
8. Who (if any body else) do you live with?	
9. In which type of residence do you currently live?	

Section 3

This section asks you to answer the questions using a 7-point scale (unless otherwise indicated) like this:

1-------------------2-----------------3----------------4-------------------5-----------------6-----------------7

1 = couldn't be worse 4 = mixed 7 = couldn't be better

2 = displeased 3 = mostly satisfied 5 = mostly satisfied 6-pleased

10. How satisfied are you with your life as a whole today?	
11. How satisfied are you with your job/training/education (main occupation)?	
12. How satisfied are you with your financial situation?	
13. Do you have anyone who you would call a close friend?	Yes/No
14. In the last week have you seen a friend? (visited or been visited or met a friend outside home and work?)	Yes/No
15. How satisfied are you with the number and quality of your friendships?	
16. How satisfied are you with your leisure activities?	
17. How satisfied are you with your accommodation?	
18. In the past year have you been accused of a crime?	Yes/No
19. In the past year have you been the victim of physical violence?	Yes/No
20. How satisfied are you with your personal safety?	
21. How satisfied are you with the people you live with? Or, if you live alone, how satisfied are you with living alone?	
22. How satisfied are you with your sex life?	
23. How satisfied are you with your relationship with your family?	
24. How satisfied are you with your health?	
25. How satisfied are you with your mental health?	

4.2 Recovery Style Questionnaire

Participant code:

Date:

Written below are a list of statements about your illness. Please read them carefully and tick one box for each question to show if you agree or disagree. There are no right or wrong answers, just what you think. Please answer all the questions.

1. There was a gradual build-up to me becoming ill.	Agree Disagree
2. My illness is not part of my personality.	Agree Disagree
3. I am responsible for what I think when I am ill.	Agree Disagree
4. I am not interested in my illness.	Agree Disagree
5. My illness taught me new things about myself.	Agree Disagree
6. I need help to solve the problems caused by my illness.	Agree Disagree
7. My illness was caused by my difficulties in coping with life.	Agree Disagree
8. I have had a nervous breakdown.	Agree Disagree
9. I can see positive aspects to my illness.	Agree Disagree
10. My illness has had a strong impact on my life.	Agree Disagree
11. I am not frightened of mental illness.	Agree Disagree
12. I liked some of the experiences I had when I was ill.	Agree Disagree
13. My illness helped me find a more satisfying life.	Agree Disagree
14. My illness came on suddenly and went suddenly.	Agree Disagree
15. My illness is part of me.	Agree Disagree
16. I am not responsible for my actions when I am ill.	Agree Disagree
17. I am curious about my illness.	Agree Disagree
18. I understand myself better because of my illness.	Agree Disagree
19. I can manage the problems caused by my illness alone.	Agree Disagree
20. Others are to blame for my illness.	Agree Disagree
21. I have had a medical illness.	Agree Disagree
22. Nothing good came from my illness.	Agree Disagree
23. My illness has had little effect on my life.	Agree Disagree
24. I am frightened of mental illness.	Agree Disagree
25. I don’t like any f the unusual experiences I had when I was ill.	Agree Disagree
26. It’s hard to find satisfaction with life since I was ill.	Agree Disagree
27. My illness came on very suddenly.	Agree Disagree

28. My illness is alien to me.	Agree Disagree
29. I am responsible for my thoughts and feelings when I am ill.	Agree Disagree
30. I don't care about my illness now that I am well.	Agree Disagree
31. I want to be the person I was before my illness.	Agree Disagree
32. Others can help me solve my problems.	Agree Disagree
33. My illness was caused by stress in my life.	Agree Disagree
34. I have suffered an emotional breakdown.	Agree Disagree
35. Being ill had good parts too.	Agree Disagree
36. I'm not really interested in my illness.	Agree Disagree
37. I liked some of the unusual ideas I had when I was ill.	Agree Disagree
38. My life is more satisfying since my illness.	Agree Disagree
39. My attitude to mental illness is better now than before I was ill.	Agree Disagree

Thank you very much!

4.3 Illness Perceptions Questionnaire for schizophrenia

Participant code:

Date:

YOUR VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS

Please tick any of the following terms that have been used to describe your mental health problems, and add any other terms that may have been used. For each term, please indicate the extent to which you would agree that this label describes the experiences you have had.

	Label/term	tick if been used	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
	Psychosis						
	Depression						
	Anxiety						
	Schizophrenia						
	Other						

Please write the term / label that you feel best describes your mental health problems:

____

Listed below are a number of experiences that you may or may not have had since your mental health problems began. Please indicate by circling Yes or No whether or not you have had each of these experiences SINCE YOUR MENTAL HEALTH PROBLEMS BEGAN. In the next column, please indicate whether you think that this experience is part of your mental health problems, due to side-effects of medication, or due to other factors. If you feel that it is due to an equal combination of these factors, then you can put a tick in more than one column.

	I have had this experience since my mental health problems			**This experience is/was:**		
	YES	**NO**		**Part of my mental health problems**	**Due to side effects of my medication**	**Due to other factors**
Being irritable	YES	NO				
Pacing	YES	NO				
Worrying	YES	NO				
Believing people can read my mind	YES	NO				
Receiving messages from the TV or media	YES	NO				
Loss of motivation	YES	NO				
Poor appetite	YES	NO				
Mood swings	YES	NO				
Being violent	YES	NO				
Being withdrawn	YES	NO				
Being secretive	YES	NO				
Sleeping a lot	*YES*	NO				
Not doing much	YES	NO				
Lack of energy	YES	NO				
Imagining things	YES	NO				
Paranoia	YES	NO				
Hearing voices	YES	NO				
Feeling restless	YES	NO				

Having thoughts I would rather not have	YES	NO				
Difficulty concentrating	YES	NO				
Being suspicious of other people	YES	NO				
Feeling I am possessed	YES	NO				
Memory problems	YES	NO				
Believing that my thoughts are being broadcast to others	YES	NO				
Feeling I am being watched	YES	NO				
Thinking people are laughing at me	YES	NO				
Believing I am a different person	YES	NO				
Gaining weight	YES	NO				
Feeling agitated	YES	NO				
Being argumentative	YES	NO				
Feeling suicidal	YES	NO				
Loss of interest in my personal care	YES	NO				
Being self-absorbed	YES	NO				
Difficulty sleeping	YES	NO				
Not helping around the house	YES	NO				
Becoming bored easily	YES	NO				
Difficulty doing everyday tasks	YES	NO				
Problems communicating with other people	YES	NO				
Being aggressive	YES	NO				
Panic attacks	YES	NO				
Loss of self confidence	YES	NO				
Feeling worthless	YES	NO				
Seeing things that are not really there	YES	NO				
Experiencing strange smells	YES	NO				
Clouded thoughts	YES	NO				
Feeling low	YES	NO				
Shakiness	YES	NO				

Talking or laughing to myself	YES	NO				
Losing touch with reality	YES	NO				
Believing I am special	YES	NO				
Anxiety	YES	NO				
Hyperactive	YES	NO				
Having bizarre thoughts	YES	NO				
Not being able to understand other people	YES	NO				
Frittering money away	YES	NO				
Senses seem heightened so that noises and colours seem more intense	YES	NO				
Excessive smoking	YES	NO				
Feeling nervous	YES	NO				

We are interested in your own personal views of how you NOW see your mental health problems. We understand that your views are likely to have changed considerably over time, but please indicate how you NOW view things.

Please indicate how much you agree or disagree with the following statements about your mental health problems by ticking the appropriate box.

	VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
IP 1	My mental health problems will last a short time					
IP 2	My mental health problem is a serious condition					
IP 3	There are some things which I can do to control my symptoms					
IP 4	There is little treatment available that can improve my mental health problems					
IP 5	I get depressed when I think about my mental health problems					

IP 6	I feel very puzzled by my mental health problems					
IP 7	My mental health problem is likely to be permanent rather than temporary					
IP 8	My mental health problem does not have much effect on my life					
IP 9	To some extent what I do can determine whether my mental health problems get better or worse					
IP 10	When I think about my mental health problems I get upset					
IP 11	My treatment will be effective in managing my mental health problems					
IP 12	I don't have any understanding of my mental health problems at all					
IP 13	My mental health problems will last for a long time					
IP 14	My mental health problems have financial consequences					
IP 15	My mental health problems make it more difficult for me to do day to day things					
IP 16	Nothing I do will affect my mental health problems at all					
IP 17	My mental health problems make me feel angry					
IP 18	The negative effects of my mental health problems can be prevented (avoided) by my treatment					
IP 19	I feel that I don't know anything about my mental health problems					
IP 20	My mental health problems will pass quickly					
IP 21	Sometimes I have more symptoms than other times					
IP 22	My mental health problems cause difficulties for those who are close to me					
IP 23	My actions will have no effect on the outcome of my mental health problems					
IP 24	My mental health problems do not worry me					

IP 25	My mental health problems make no sense to me at all					
IP 26	I expect to have this mental health problem for the rest of my life					
IP 27	I don't get on as well with my family since my mental health problems					
IP 28	If I tried harder I could control my symptoms					
IP 29	Having this mental health problem makes me feel anxious					
IP 30	My treatment can control my mental health problems					
IP 31	I have a clear picture or understanding of my mental health problems					
IP 32	I have times when I am well and times when I am not so well					
IP 33	My mental health problems have messed up my social life					
IP 34	I could do more to help myself					
IP 35	My mental health problems mean that I am valued less by other people					
IP 36	My mental health problems make me feel afraid					
IP 37	There is no treatment that can help with my condition					
IP 38	Sometimes the symptoms of my mental health problems are worse than other times					
IP 39	My mental health problems make working very difficult					
IP 40	If I was a stronger person I would get better					
IP 41	My mental health problems make me feel worthless					
IP 42	Some of my symptoms will be there all the time but others will come and go					
IP 43	I have lost important relationships as a result of my mental health problems					

IP 44	I get very frustrated by my mental health problems					
IP 45	My mental health problems have had some positive effects on my life					
IP 46	My mental health problems will improve in time					
IP 47	I feel a sense of loss due to my mental health problems					

CAUSES OF MY MENTAL HEALTH PROBLEMS

We are interested in what you consider may have been the causes of your mental health problems. As people are very different, there is no correct answer for this question. We are most interested in your own views rather than what others including doctors or family may have suggested to you.

Below is a list of possible causes for your mental health problems. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	Possible Causes	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
C1	Stress or worry					
C2	Hereditary; it runs in my family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My family's behaviour					

C10	My mental attitude, e.g., thinking about life negatively					
C11	Family problems					
C12	Overwork					
C13	Alcohol					
C14	Taking illicit drugs					
C15	My personality					
C16	Brain damage or abnormality					
C17	Lack of friends or people who cared about me					
C18	Chemical imbalance in the brain					
C19	A trauma; something disturbing or shocking that happened in my life					
C20	Death of a loved one					
C21	Money worries					
C22	Someone spiked my drink with illicit drugs					
C23	Lack of sleep					
C24	Thinking about things too much					
C25	My upbringing					
C26	Being bullied at school					

Below, please list in rank order the three most important factors that you now believed caused YOUR mental health problems. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:

1.____

2.____

3.____

Thank you very much for completing this questionnaire

4.4 Illness Perceptions Questionnaire for schizophrenia – subscale items

Cause Items
- Stress or worry
- Hereditary; it runs in my family
- A germ or virus
- Diet or eating habits
- Chance or bad luck
- Poor medical care in my past
- Pollution in the environment
- My own behaviour
- My family's behaviour
- Money worries
- Family problems
- Overwork
- Alcohol
- Taking illicit drugs
- My personality
- Brain damage or abnormality
- Lack of friends or people who cared about me
- Chemical imbalance in the brain
- Death of a loved one
- Lack of sleep
- Thinking about things too much
- My upbringing
- Being bullied at school
- My mental attitude, e.g., thinking about life negatively
- A trauma; something disturbing or shocking that happened in my life
- Someone spiked my drink with illicit drugs

Timeline acute/chronic
- My mental health problems will last a short time (R)
- My mental health problems are likely to be permanent rather than temporary
- My mental health problems will last for a long time.
- My mental health problems will pass quickly (R).
- I expect to have these mental health problems for the rest of my life
- My mental health problems will improve in time (R)

Timeline cyclical
- Sometimes I have more symptoms than other times.
- I have times when I am well and times when I am not so well.
- Sometimes the symptoms of my mental health problems are worse than other times
- Some of my symptoms will be there all the time but others will come and go.

Consequences
- My mental health problem is a serious condition.
- My mental health problems do not have much effect on my life. (R).
- My mental health problems have financial consequences for me.
- My mental health problems make it more difficult for me to do day to day things.
- My mental health problems cause difficulties for those who are close to me.
- I don't get on as well with our family since their mental health problems.
- My mental health problems have messed up my social life.
- My mental health problems mean that I am valued less by other people.
- My mental health problems make working very difficult for me.
- I have lost important relationships as a result of my mental health problems.
- My mental health problems have had some positive effects on my life (R).

Personal Control
- There are some things that I can do to control my symptoms.
- To some extent, what I do can determine whether my mental health problems get better or worse
- Nothing I do will affect my mental health problems (R)
- My actions will have no effect on the outcome of my mental health problems (R)
- Personal Blame
- If I tried harder I could control my symptoms
- I could do more to help myself
- If I were a stronger person, I would get better

Treatment Control
- There is little treatment available that can improve my mental health problems (R)
- My treatment will be effective in managing my mental health problems.
- The negative effects of my mental health problems can be prevented (avoided) by my treatment
- My treatment can control my mental health problems.
- There is no treatment that can help with my condition (R)

Illness Coherence
- I feel very puzzled by my mental health problems.
- I don't have any understanding of my mental health problems at all
- I feel that I don't know anything about my mental health problems
- My mental health problems make no sense to me at all
- I have a clear picture or understanding of my mental health problems (R)

Emotional Representation
- I get depressed when I think about my mental health problems
- When I think about my mental health problems I get upset
- My mental health problems make me feel angry
- My mental health problems do not worry me (R)
- My mental health problems make me feel anxious
- My mental health problems make me feel afraid
- My mental health problems make me feel worthless
- I get very frustrated by my mental health problems
- I feel a sense of loss due to my mental health problems

(R) = item is reverse scored

Appendix 5

Staff Questionnaires

5.1 Bexley Engagement Scale

BEXLEY ENGAGEMENT MEASURE

Engagement is the process of building a trusting relationship between a mental health worker and client. The BEM aims to measure the degree to which this relationship has formed at any point in time.

Date:
Client's name:
Completed by:
Relationship to client:

Over the last month,

Contact

How often is it possible to have planned contact with the person?

4 always 3 usually 2 sometimes 1 rarely 0 never

Participation

How often does the person participate with you in a shared activity that does not require them to share much about themself, e.g. going to the shops?

4 always 3 usually 2 sometimes 1 rarely 0 never

Collaboration

How often does the person collaborate with you in completing a task that requires them to share significant things about themself, e.g. filling in a form?

4 always 3 usually 2 sometimes 1 rarely 0 never

Openness

How often does the person talk openly about their thoughts and feelings?

4 always 3 usually 2 sometimes 1 rarely 0 never

Help seeking

How often does the person ask for your help and advice?

4 always 3 usually 2 sometimes 1 rarely 0 never

Treatment

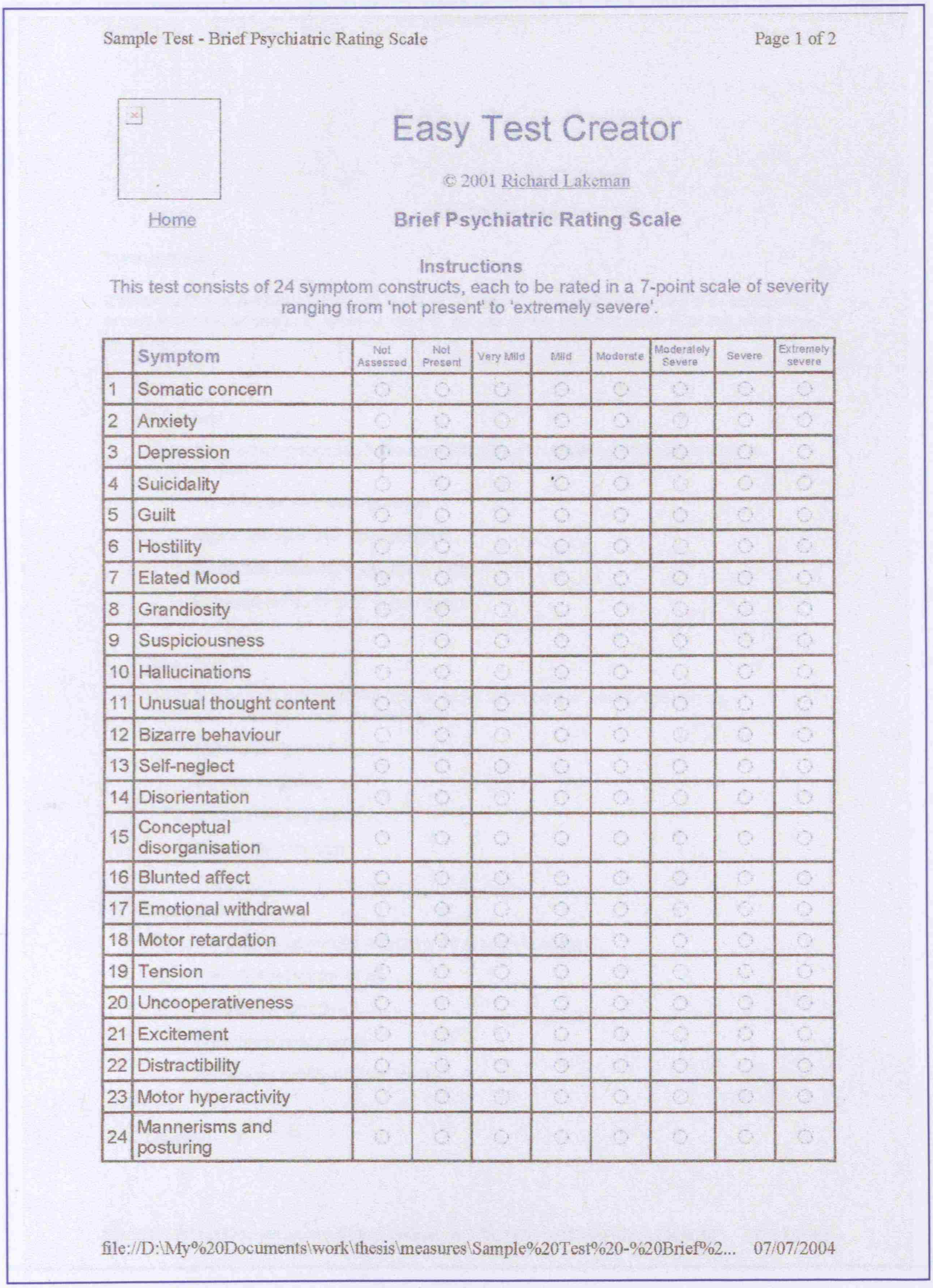
How often does the person enter into negotiation about treatment options e.g. psychotropic medication, psychotherapy?

4 always 3 usually 2 sometimes 1 rarely 0 never

Total Score

Add the score on each domain ________

5.2 *Brief Psychiatric Rating Scale*



Sample Test - Brief Psychiatric Rating Scale Page 1 of 2

Home

Easy Test Creator

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Brief Psychiatric Rating Scale

Instructions

This test consists of 24 symptom constructs, each to be rated in a 7-point scale of severity ranging from 'not present' to 'extremely severe'.

	Symptom	Not Assessed	Not Present	Very Mild	Mild	Moderate	Moderately Severe	Severe	Extremely severe
1	Somatic concern	○	○	○	○	○	○	○	○
2	Anxiety	○	○	○	○	○	○	○	○
3	Depression	○	○	○	○	○	○	○	○
4	Suicidality	○	○	○	○	○	○	○	○
5	Guilt	○	○	○	○	○	○	○	○
6	Hostility	○	○	○	○	○	○	○	○
7	Elated Mood	○	○	○	○	○	○	○	○
8	Grandiosity	○	○	○	○	○	○	○	○
9	Suspiciousness	○	○	○	○	○	○	○	○
10	Hallucinations	○	○	○	○	○	○	○	○
11	Unusual thought content	○	○	○	○	○	○	○	○
12	Bizarre behaviour	○	○	○	○	○	○	○	○
13	Self-neglect	○	○	○	○	○	○	○	○
14	Disorientation	○	○	○	○	○	○	○	○
15	Conceptual disorganisation	○	○	○	○	○	○	○	○
16	Blunted affect	○	○	○	○	○	○	○	○
17	Emotional withdrawal	○	○	○	○	○	○	○	○
18	Motor retardation	○	○	○	○	○	○	○	○
19	Tension	○	○	○	○	○	○	○	○
20	Uncooperativeness	○	○	○	○	○	○	○	○
21	Excitement	○	○	○	○	○	○	○	○
22	Distractibility	○	○	○	○	○	○	○	○
23	Motor hyperactivity	○	○	○	○	○	○	○	○
24	Mannerisms and posturing	○	○	○	○	○	○	○	○

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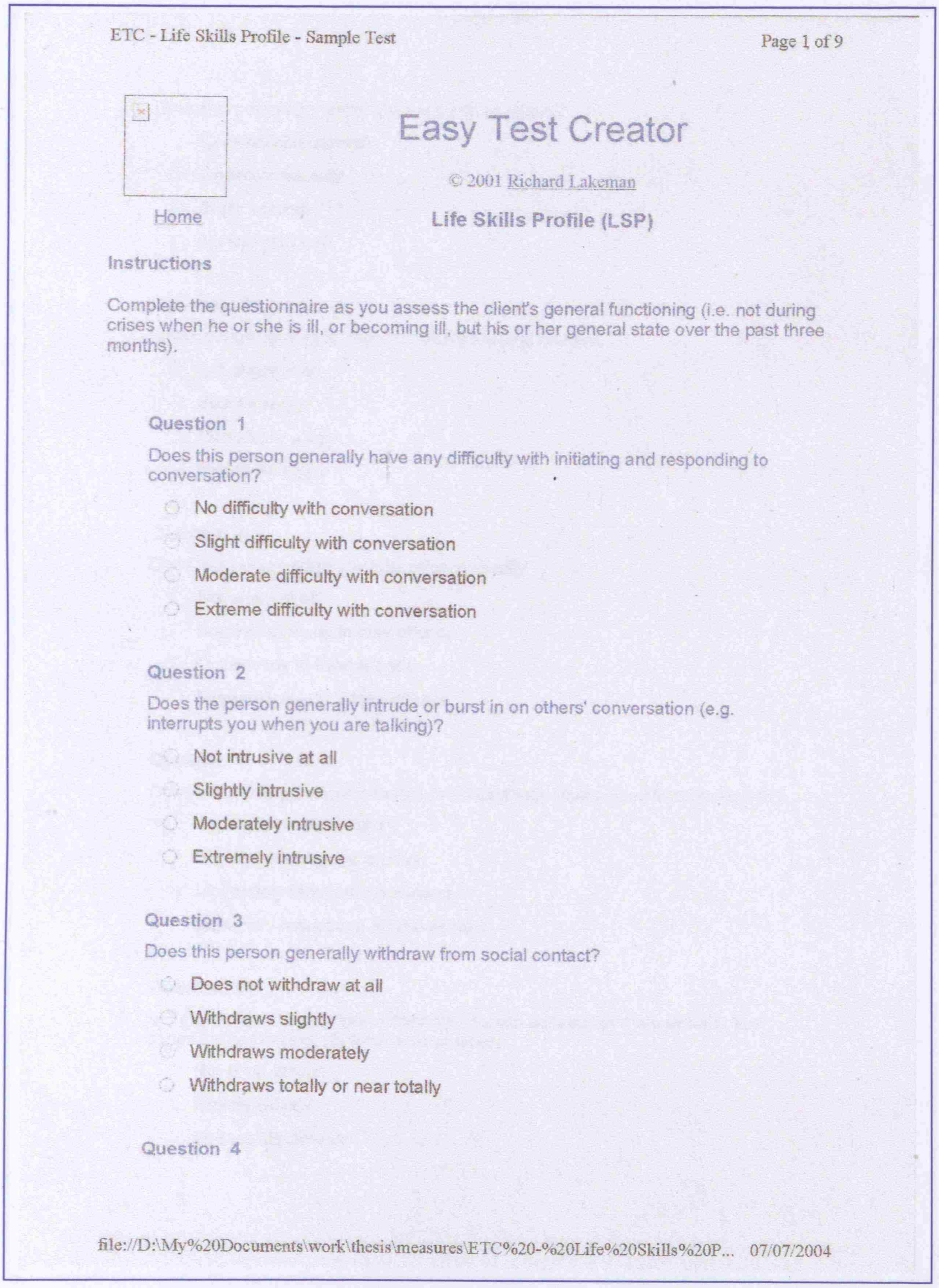
5.3 Life Skills Profile



ETC - Life Skills Profile - Sample Test

Page 1 of 9

Easy Test Creator

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Home

Life Skills Profile (LSP)

Instructions

Complete the questionnaire as you assess the client's general functioning (i.e. not during crises when he or she is ill, or becoming ill, but his or her general state over the past three months).

Question 1

Does this person generally have any difficulty with initiating and responding to conversation?

○ No difficulty with conversation
○ Slight difficulty with conversation
○ Moderate difficulty with conversation
○ Extreme difficulty with conversation

Question 2

Does the person generally intrude or burst in on others' conversation (e.g. interrupts you when you are talking)?

○ Not intrusive at all
○ Slightly intrusive
○ Moderately intrusive
○ Extremely intrusive

Question 3

Does this person generally withdraw from social contact?

○ Does not withdraw at all
○ Withdraws slightly
○ Withdraws moderately
○ Withdraws totally or near totally

Question 4

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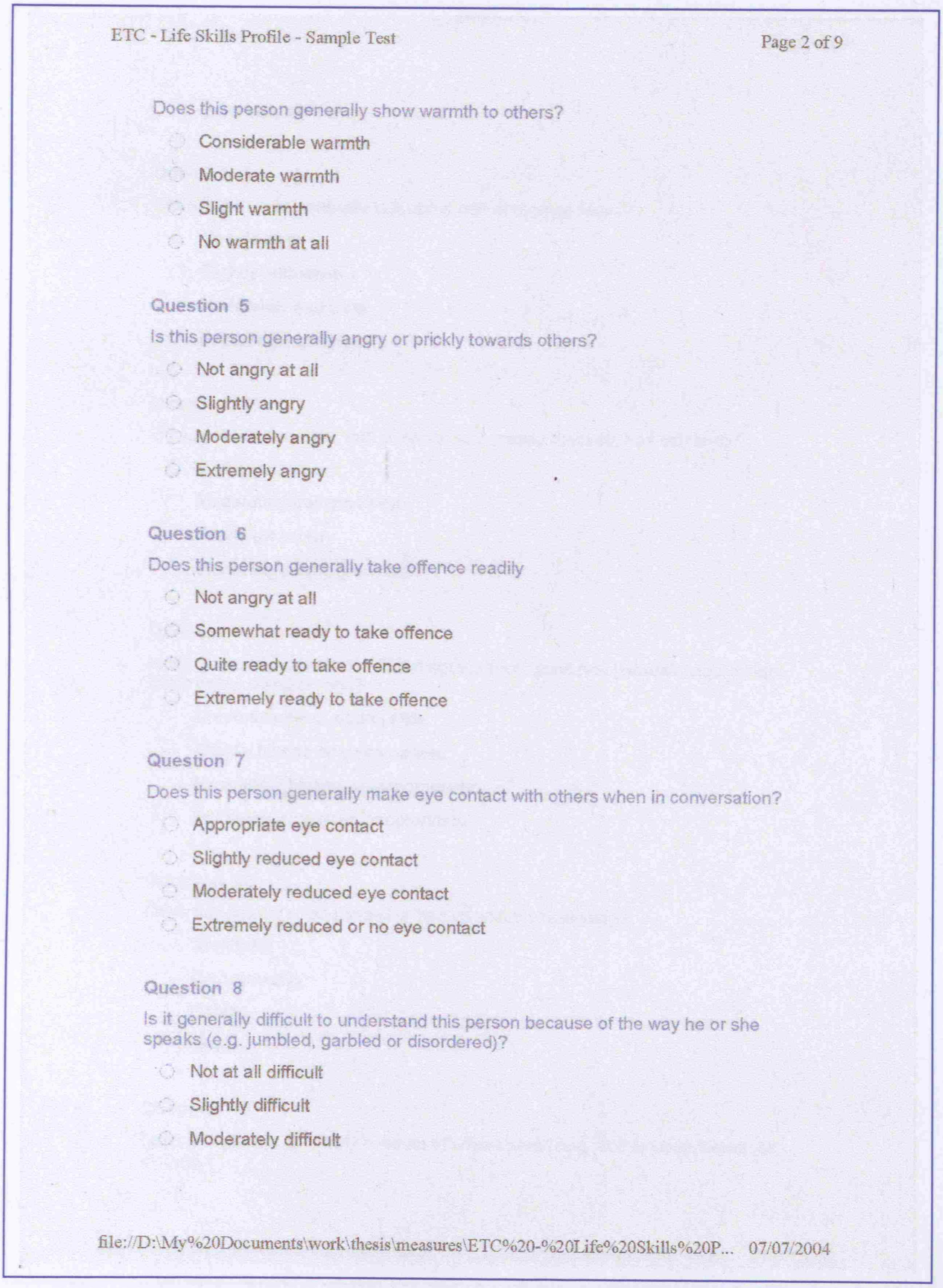

ETC - Life Skills Profile - Sample Test

Page 2 of 9

Does this person generally show warmth to others?

○ Considerable warmth
○ Moderate warmth
○ Slight warmth
○ No warmth at all

Question 5

Is this person generally angry or prickly towards others?

○ Not angry at all
○ Slightly angry
○ Moderately angry
○ Extremely angry

Question 6

Does this person generally take offence readily

○ Not angry at all
○ Somewhat ready to take offence
○ Quite ready to take offence
○ Extremely ready to take offence

Question 7

Does this person generally make eye contact with others when in conversation?

○ Appropriate eye contact
○ Slightly reduced eye contact
○ Moderately reduced eye contact
○ Extremely reduced or no eye contact

Question 8

Is it generally difficult to understand this person because of the way he or she speaks (e.g. jumbled, garbled or disordered)?

○ Not at all difficult
○ Slightly difficult
○ Moderately difficult

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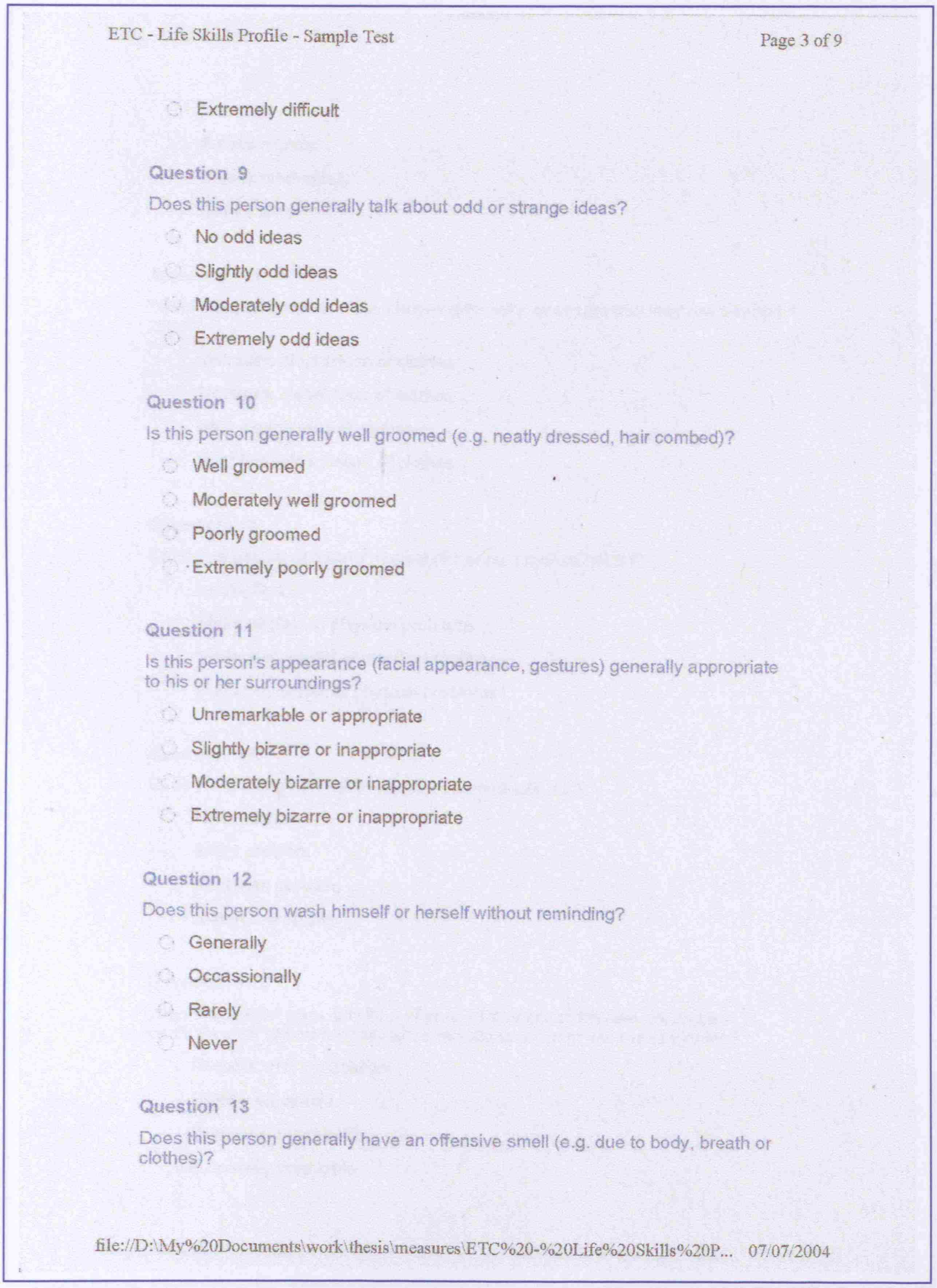

ETC - Life Skills Profile - Sample Test

Page 3 of 9

○ Extremely difficult

Question 9

Does this person generally talk about odd or strange ideas?

○ No odd ideas

○ Slightly odd ideas

○ Moderately odd ideas

○ Extremely odd ideas

Question 10

Is this person generally well groomed (e.g. neatly dressed, hair combed)?

○ Well groomed

○ Moderately well groomed

○ Poorly groomed

○ Extremely poorly groomed

Question 11

Is this person's appearance (facial appearance, gestures) generally appropriate to his or her surroundings?

○ Unremarkable or appropriate

○ Slightly bizarre or inappropriate

○ Moderately bizarre or inappropriate

○ Extremely bizarre or inappropriate

Question 12

Does this person wash himself or herself without reminding?

○ Generally

○ Occassionally

○ Rarely

○ Never

Question 13

Does this person generally have an offensive smell (e.g. due to body, breath or clothes)?

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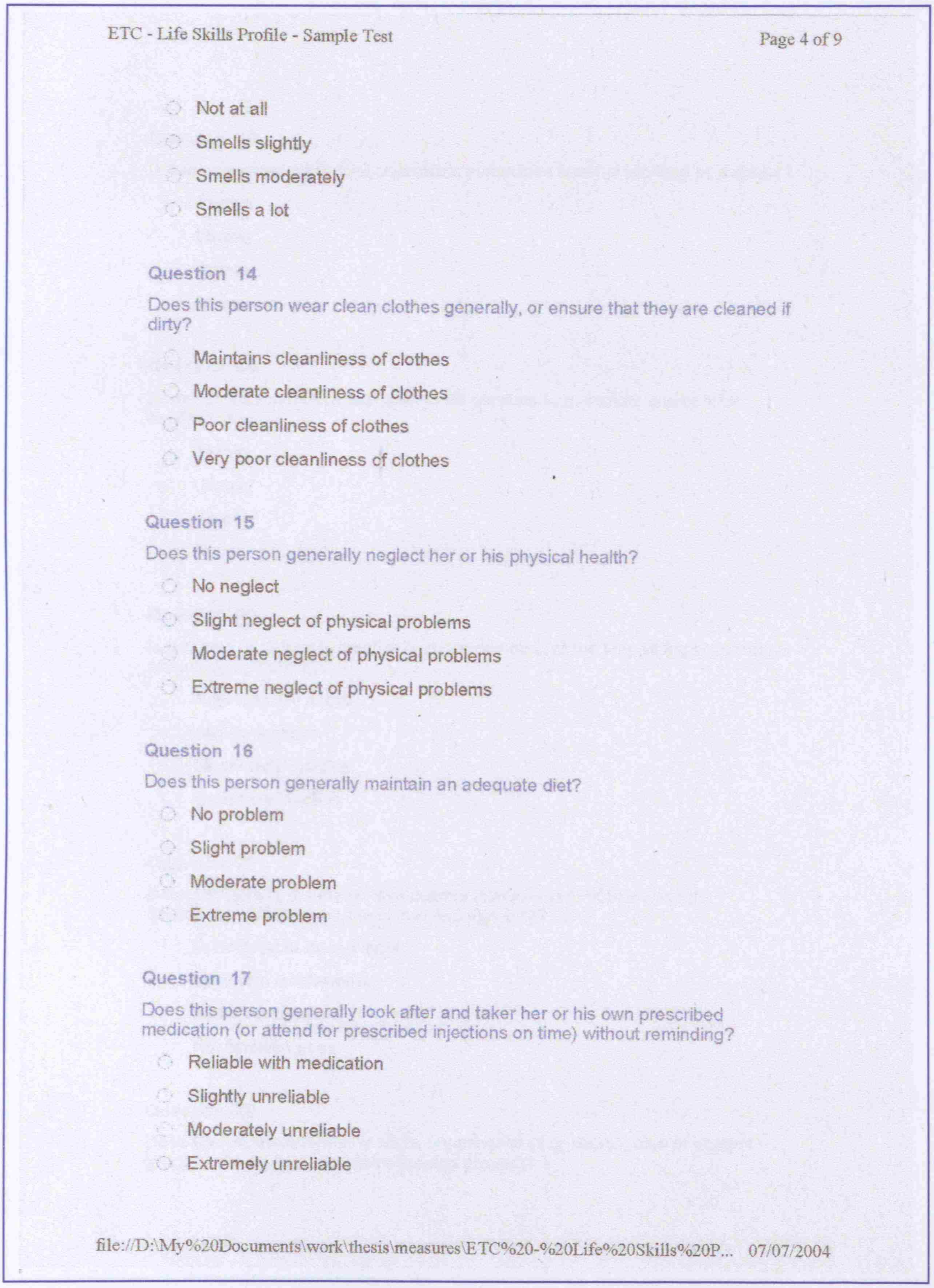

ETC - Life Skills Profile - Sample Test Page 4 of 9

○ Not at all
○ Smells slightly
○ Smells moderately
○ Smells a lot

Question 14

Does this person wear clean clothes generally, or ensure that they are cleaned if dirty?

○ Maintains cleanliness of clothes
○ Moderate cleanliness of clothes
○ Poor cleanliness of clothes
○ Very poor cleanliness of clothes

Question 15

Does this person generally neglect her or his physical health?

○ No neglect
○ Slight neglect of physical problems
○ Moderate neglect of physical problems
○ Extreme neglect of physical problems

Question 16

Does this person generally maintain an adequate diet?

○ No problem
○ Slight problem
○ Moderate problem
○ Extreme problem

Question 17

Does this person generally look after and taker her or his own prescribed medication (or attend for prescribed injections on time) without reminding?

○ Reliable with medication
○ Slightly unreliable
○ Moderately unreliable
○ Extremely unreliable

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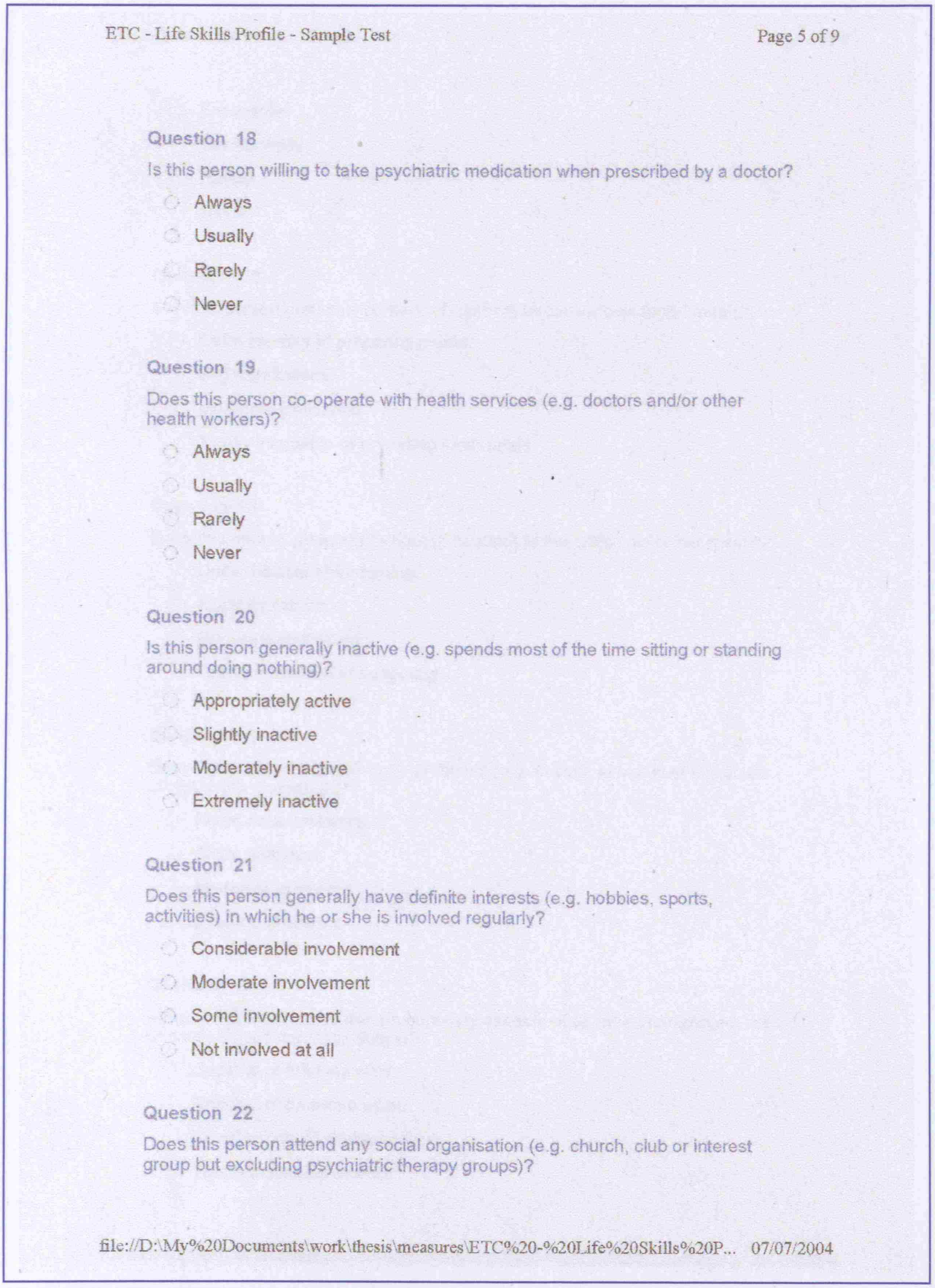

ETC - Life Skills Profile - Sample Test

Page 5 of 9

Question 18

Is this person willing to take psychiatric medication when prescribed by a doctor?

- ○ Always
- ○ Usually
- ○ Rarely
- ○ Never

Question 19

Does this person co-operate with health services (e.g. doctors and/or other health workers)?

- ○ Always
- ○ Usually
- ○ Rarely
- ○ Never

Question 20

Is this person generally inactive (e.g. spends most of the time sitting or standing around doing nothing)?

- ○ Appropriately active
- ○ Slightly inactive
- ○ Moderately inactive
- ○ Extremely inactive

Question 21

Does this person generally have definite interests (e.g. hobbies, sports, activities) in which he or she is involved regularly?

- ○ Considerable involvement
- ○ Moderate involvement
- ○ Some involvement
- ○ Not involved at all

Question 22

Does this person attend any social organisation (e.g. church, club or interest group but excluding psychiatric therapy groups)?

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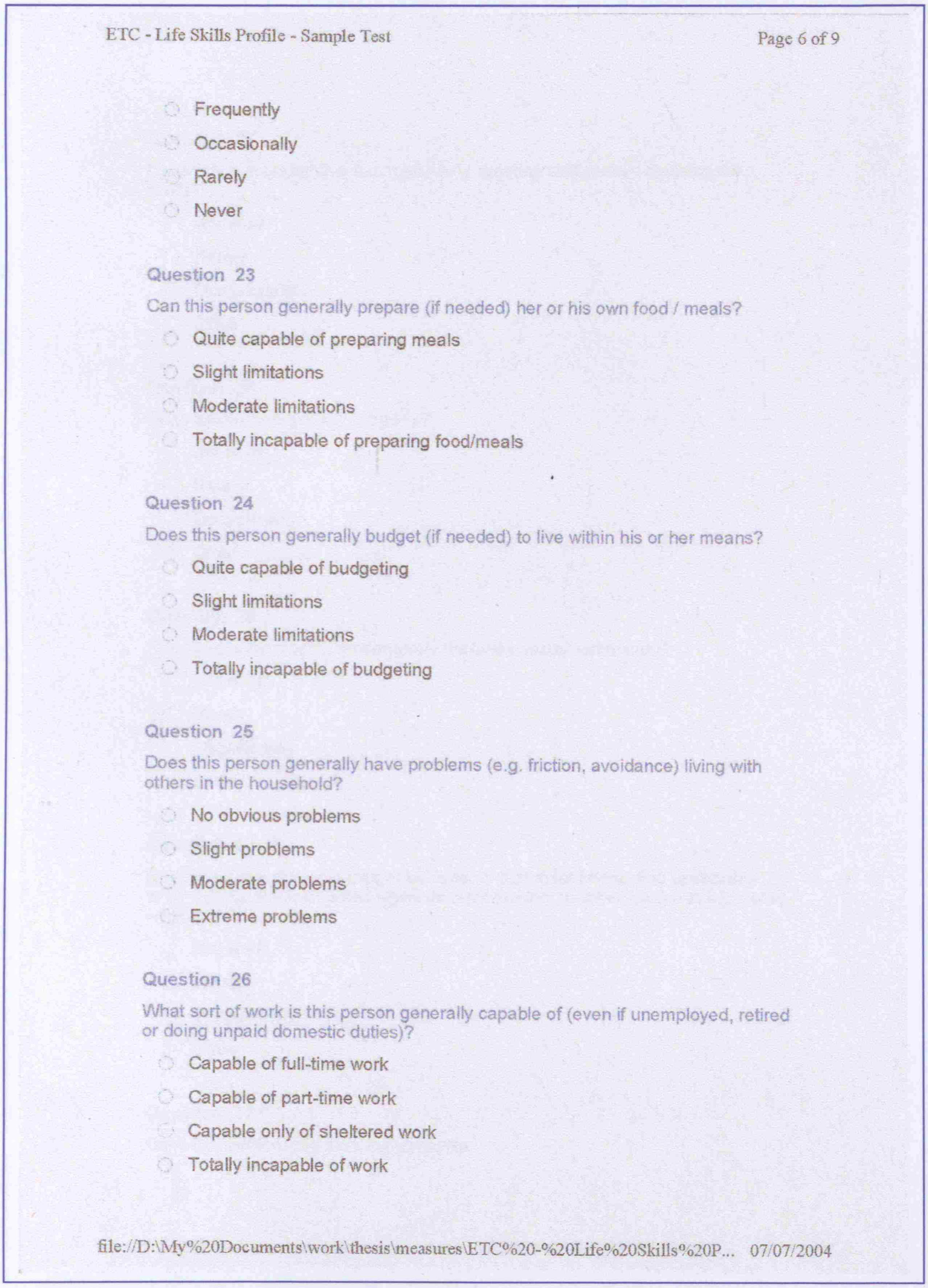


○ Frequently

○ Occasionally

○ Rarely

○ Never

Question 23

Can this person generally prepare (if needed) her or his own food / meals?

○ Quite capable of preparing meals

○ Slight limitations

○ Moderate limitations

○ Totally incapable of preparing food/meals

Question 24

Does this person generally budget (if needed) to live within his or her means?

○ Quite capable of budgeting

○ Slight limitations

○ Moderate limitations

○ Totally incapable of budgeting

Question 25

Does this person generally have problems (e.g. friction, avoidance) living with others in the household?

○ No obvious problems

○ Slight problems

○ Moderate problems

○ Extreme problems

Question 26

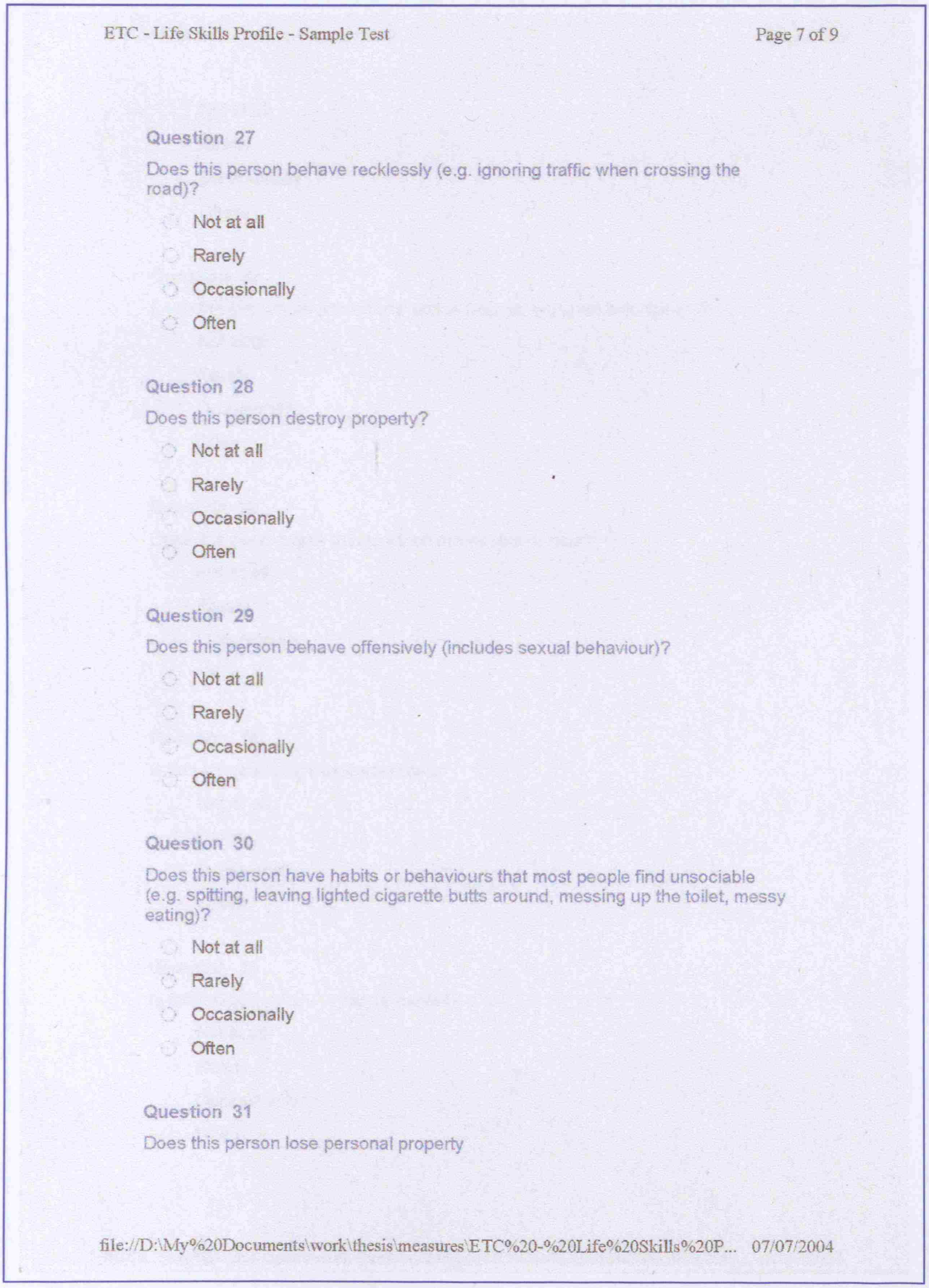
What sort of work is this person generally capable of (even if unemployed, retired or doing unpaid domestic duties)?

○ Capable of full-time work

○ Capable of part-time work

○ Capable only of sheltered work

○ Totally incapable of work



ETC - Life Skills Profile - Sample Test

Page 7 of 9

Question 27

Does this person behave recklessly (e.g. ignoring traffic when crossing the road)?

○ Not at all
○ Rarely
○ Occasionally
○ Often

Question 28

Does this person destroy property?

○ Not at all
○ Rarely
○ Occasionally
○ Often

Question 29

Does this person behave offensively (includes sexual behaviour)?

○ Not at all
○ Rarely
○ Occasionally
○ Often

Question 30

Does this person have habits or behaviours that most people find unsociable (e.g. spitting, leaving lighted cigarette butts around, messing up the toilet, messy eating)?

○ Not at all
○ Rarely
○ Occasionally
○ Often

Question 31

Does this person lose personal property

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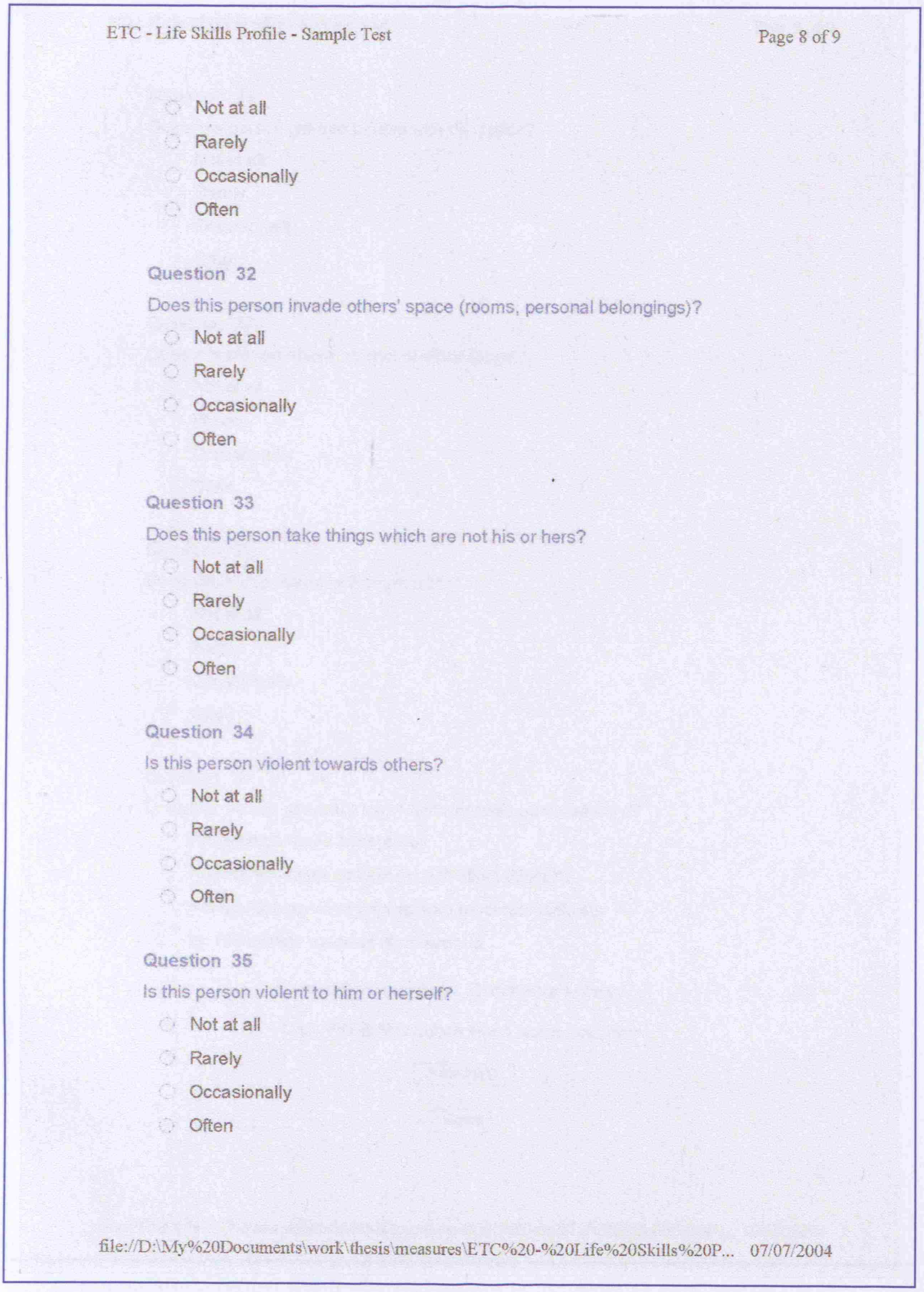

ETC - Life Skills Profile - Sample Test

Page 8 of 9

- ○ Not at all
- ○ Rarely
- ○ Occasionally
- ○ Often

Question 32

Does this person invade others' space (rooms, personal belongings)?

- ○ Not at all
- ○ Rarely
- ○ Occasionally
- ○ Often

Question 33

Does this person take things which are not his or hers?

- ○ Not at all
- ○ Rarely
- ○ Occasionally
- ○ Often

Question 34

Is this person violent towards others?

- ○ Not at all
- ○ Rarely
- ○ Occasionally
- ○ Often

Question 35

Is this person violent to him or herself?

- ○ Not at all
- ○ Rarely
- ○ Occasionally
- ○ Often

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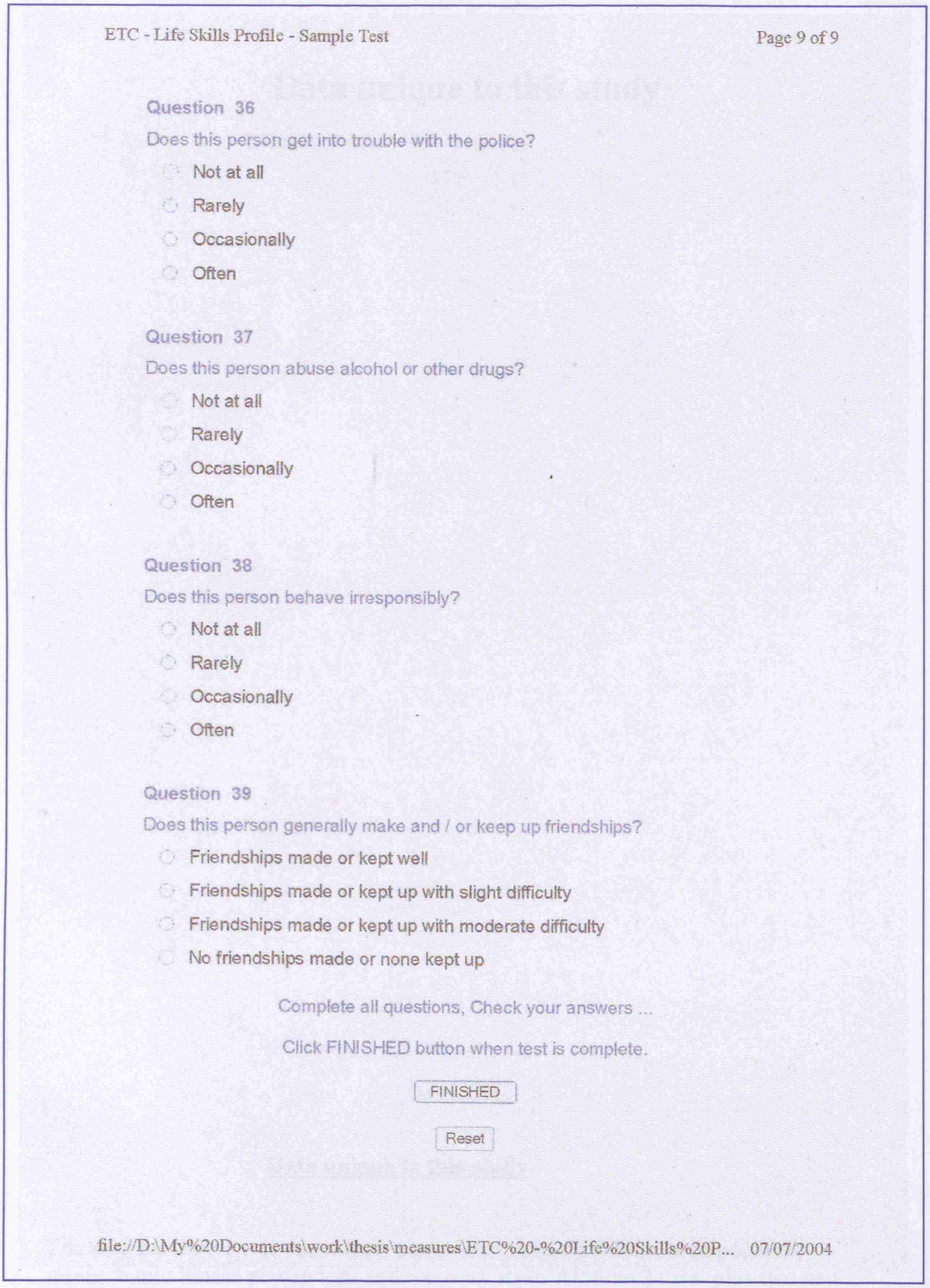

ETC - Life Skills Profile - Sample Test

Page 9 of 9

Question 36

Does this person get into trouble with the police?

- ○ Not at all
- ○ Rarely
- ○ Occasionally
- ○ Often

Question 37

Does this person abuse alcohol or other drugs?

- ○ Not at all
- ○ Rarely
- ○ Occasionally
- ○ Often

Question 38

Does this person behave irresponsibly?

- ○ Not at all
- ○ Rarely
- ○ Occasionally
- ○ Often

Question 39

Does this person generally make and / or keep up friendships?

- ○ Friendships made or kept well
- ○ Friendships made or kept up with slight difficulty
- ○ Friendships made or kept up with moderate difficulty
- ○ No friendships made or none kept up

Complete all questions, Check your answers ...

Click FINISHED button when test is complete.

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Appendix 6

Data unique to this study

Data unique to this study

The data for time 1 was taken from a previous trainee's (Manuela Sapochnik) research into illness perceptions and recovery style. All time 2 data, plus two new participants who were recruited into the study and assessed six months apart, was unique to this study.