STIGMATISATION OF PEOPLE
WITH SCHIZOPHRENIA

A Thesis Submitted for the Degree of PhD at the University of London

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Abstract

This thesis examines stigmatisation, in particular that of schizophrenia, the relationship between stigmatisation and language, the origins of stigmatisation and routes to de-stigmatisation. It includes a historical perspective on the work on stigmatisation and its theoretical developments as well as an exploration of the links between stigmatisation and the prognosis of schizophrenia.

The linguistic study covers the relationship between language and social factors, language as discourse, language and identity, language and classifications, stigmatisation and psychiatric classifications, language in relation to the stigmatisation of schizophrenia, metalinguistics, and defence tactics against stigmatisation. The chapter on the origins of stigmatisation explores the constitutional, psychological, economic and evolutionary roots and presents a new unitary theory of stigmatisation.

In the thesis, are presented the results of a study of perceived stigmatisation and predisposition to enact stigmatisation in 107 patients with schizophrenia and 151 of patients’ relatives from South Camden and Islington. The factor analysis of the results derives three factors which indicate basic attitudes linked to the origins of stigmatisation. These factors support the idea that the underlying origin of stigmatisation is embedded within psychological, economic and genetic domains. Also, the highest unanimity in de-stigmatisation was noted in their response to questions with the highest ‘self-interest value’ which supports the unitary theory of stigmatisation. Another result of this study is the development of a new stigmatisation scale for future research.
The study also explores patients’ and relatives’ discourse to discover their feelings, anxieties, needs, beliefs, attitudes about illness and cure, explanatory models, self-image, notions of agency, their use of terms as discourse for compensatory purposes, their deconstruction of the concept of schizophrenia and defence mechanisms against stigmatisation.

Finally, the thesis examines routes to de-stigmatisation and various measures to be used in anti-stigmatisation campaigns. These include educational, psychological, political, legislative, linguistic, intellectual and cultural interventions.
Acknowledgment

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Finally, I would like to especially thank Professor Roland Littlewood whose support, encouragement and inspiration are reflected in this work. It was him who encouraged me to enroll on a PhD programme, who supported my application for a grant and who helped me develop my initiative and thoughts.

This work is dedicated to the Stigma Campaign of the Royal College of Psychiatrists.
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List of Abbreviations

CAMI = Community Attitudes to Mental Illness
CMHI = Community Mental Health Ideology
CMI = Custodial Mental Illness Ideology
DF = Degree of Freedom
DSM-IV = Diagnostic and Statistical Manual, Fourth Edition
EE = Expressed Emotion
ESD = Enhanced Social desirability
ESP = Especially
IPSS = International Pilot Study of Schizophrenia
MACA = Mental After-Care Association
NIMH = National Institute of Mental Health
NS = Not Significant
NSF = National Schizophrenia Fellowship
OMI = Opinion about Mental Illness
PAS = Patient Administration System
Path. = Pathology
PD = Personality Disorder
Pl. = Plural
p. = Page
pp. = Pages
SCAN = Schedule for Clinical Assessment in Neuropsychiatry
SD = Social Desirability
Sig. = Significance
WHO = World Health Organisation
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CHAPTER I

AN INTRODUCTION TO STIGMATISATION
### 1.1 The Etymology of Stigma

The word stigma is Greek in origin and, as a noun, denotes a mark made by a pointed instrument.

The corresponding verb means ‘to prick’ or ‘puncture’ (Oxford English Dictionary, 1994). The same dictionary defines stigma as:

“1. A mark made upon the skin by burning with a hot iron (rarely, by cutting or pricking) as a token of infamy or subjection; a brand...

1863 W. H. Russell *Diary North & South*. I. 246 The advertisements for runaway negroes...the description of the stigmata on their persons—whippings and brandings, scars and cuts...

2. A mark of disgrace or infamy; a sign of severe censure or condemnation, regarded as impressed on a person or thing.

1777 Chatham, *Speech on [Royal] Address*, 18 Nov. I..call upon your Lordships..to stamp upon it an indelible stigma of the public abhorrence...

3. A distinguishing mark or characteristic (of a bad or objectionable kind); in Path. [Pathology]

a sign of some specific disorder, as hysteria.

1897 Allbutt’s *Systematic Medicine*. II. 889. The stigmas of a morphinist are plausibility
and disorderliness...

4. *pl. [Plural]* Marks resembling the wounds on the crucified body of Christ, said to have been supernaturally impressed on the bodies of certain saints and other devout persons. Sometimes extended to other marks, as crosses, sacred names, etc., supposed to be supernaturally impressed.

1841 Earl of Shrewsbury *Letter to A. L. Phillipps* 6. Her confessor then told us that she had the stigmata on her hands, feet, and side...

5. *nonce-use.* Ineffaceable stains of blood, supposed to remain on the floor of a room where a murder has been committed.

6. *Path.* A morbid spot, dot, or point on the skin, esp. one which bleeds spontaneously...”

Five of the above definitions imply disgrace, infamy, badness, disorder, crime or morbidity. Only one (number 4) connotes sacredness yet the corresponding stigma needs to be impressed by Providence as if only the supernatural could overcome the original connotations of the word and turn it into a ‘positive’ concept.

The Webster Third New International Dictionary’s (2000) definitions of stigma and some of its quotations overlap with those of the Oxford English Dictionary. The quotations are illustrative: “when a burning iron is put on the face of an evildoer, it leaveth behind it a T stigma — Samuel Rutherford”. “The stigma of personal cowardice — William Peden.” “The pathos and the stigma of slavery — W. L. Sperry”. Stigma is defined as “a mark or label indicating deviation from a
norm” and “a symptom of a physical or mental disorder.”

In an in-depth study of stigma, considering the scientific meanings of the word does not seem to be far-fetched. In Zoology ‘stigma’ denotes each of respiratory openings or breathing-pores in insects and other invertebrates. It also means the part of a Graafian follicle where it ruptures to discharge the ovum; the mark or spot made by the enlargement of an empty tube in the wings of insects; and, a part of the pistil in flowering plants which receives the pollen in impregnation. One can see that in Biology ‘stigma’ has connotations of ‘feminity’ or ‘hollowness’. This brings one to ask about the meaning of stigma in more basic sciences. In Geometry ‘stigma’ is a point whose movement in a certain plane is determined by that of another point (the index). As such even in Geometry stigma has connotations of inferiority and subordinateness.

1.2 Is There Any Stigmatisation? A Perspective on a Conflict

Interest in the concept of stigma started to develop gradually in Sociology and Social Psychology during the first half of the twentieth century, though not always with an explicit reference to the term. Examples of workers on the subject are Riper (1939, on stuttering); Warner, (1937 on mental illness) and Zawadski & Lazarsfeld (1935, on unemployment).

After the Second World War with the extermination of nearly six million Jews by the Nazi regime and sterilization of more than two million people deemed handicapped and inferior, and later on, along with the black movement for equal rights in the United States, a number of psychologists, social psychologists and sociologists (e.g., Ladieu et al, 1947; Lewin, 1948; Meyerson, 1948;
Lemert, 1948; Cumming & Cumming, 1957; Nunnally, 1961) concentrated on understanding stigmatisation which again was not necessarily considered under this term but as institutionalisation, labelling or tertiary handicap.

In the 1960s, Goffman, a Professor of Sociology at the University of California, reviewed extensively the work already done on the subject and presented his own ideas along with his review in an essay entitled ‘Stigma: Notes on the Management of Spoilt Identity’ (Goffman, 1963). This was the first systematic work on the subject portraying the damage to people’s self-concept and restriction to their life chances that stigmatisation can cause. Within a few years, other theorists placed particular emphasis on the process of labelling (Scheff, 1966) to the extent of asserting that the label itself produces mental illness in that it crystallises the non-conformist or deviant behaviour of the one labelled into an illness behaviour which is then stabilised by social constraints and internalised by the labelled person as chronic mental illness.

The work of Scheff and Goffman provoked a huge controversy in psychiatric and sociological arenas and as time went on two groups of investigators and theoreticians were distinguished: a ‘pessimistic’ group emphasising the existence of stigmatisation and an ‘optimistic’ one de-emphasising it (Rabkin, 1974), some virtually proclaiming that stigmatisation did not exist. Theories of stigmatisation and labelling had originally come from sociologists and there was concern in some psychiatric circles that these ideas were going to jeopardise and contradict the medical model of mental illness. Acrimonious debates had already started and official psychiatric organisations were not late to take a position.

In 1972, the National Institute of Mental Health (NIMH) published a handbook for the family of
patients, not explicitly referring to the controversy, but evidently declaring its official position in an incredible language: “A person does not *have* schizophrenia as he might have an ulcer in his stomach or a cold in his head. He *is* schizophrenic; he *is* the disorder. It pervades its entire being” (NIMH, 1972, p. 5). A considerable number of scientists, psychiatrists and sociologists had already endorsed the official position or were soon to join. Gove & Fain (1973) concluded that the majority of patients in psychiatric hospitals were not seriously concerned with stigmatisation. Freeman & Simmons (1961) came to similar conclusions about patients’ relatives. Bentz & Edgerton (1971) decided that the stigmatisation of mental illness did not exist, and Crocetti, Spiro and Siassi (1974) asserted that perception of stigmatisation by patients was simply the result of their own psychopathology. Clausen (1981) concluded that feelings of stigmatisation were a consequence of patients’ self-doubts and indeed were “chronic manifestations of mental illness” itself. The reaction to Goffman and Scheff’s ideas was straightforward: feelings of stigmatisation was the result of patients’ own paranoia rather than a social response.

Yet, Crocetti et al and Clausen and dozens of others did not think that, even if one were to accept their assertion about the effect of patients’ psychopathology, there was still another time-honoured fact — just because there is ‘paranoia’ one could not conclude there is no tyrant. Numerous social and historical facts could testify to this common sense belief yet efforts to demonstrate that stigmatisation was merely part of patients’ persecuted mental state continued and soon was complemented by another theory to justify social responses rejecting of patients. Lehman et al (1976) proclaimed that any rejection was due to patients’ own bizarre, disruptive and deviant behaviours rather than labelling and stigmatisation. Though other investigators were demonstrating that labels had significant effects in eliciting stigmatisation and/or restricting life chances of patients with mental illness (e.g., Farina & Ring, 1965; Lawner, 1966; Farina et al,
1971; Farina & Felner, 1973; Loman & Larkin, 1976; Page, 1977) and research continued to
demonstrate stigmatisation in other social spheres especially in relation to women (e.g., Millett,
1970) and racism (e.g., Katz et al, 1975), a long chain of experiments started by Philips (1964)
and continued by Kirk (1974) and Lehman et al (1976) and a dozen others all concluded that
patients’ own behaviour was a significantly more potent indicator of stigmatisation than labels.

These arguments which mainly originated from either a misunderstanding of the concept of
stigmatisation or misinterpretation of the results of label-versus-behaviour experiments tended to
allay general guilt and anxiety related to feelings of being a ‘labeller’ or an ‘unfair stigmatiser’ and
fuelled further the official NIMH position to such a degree that a 1980 NIMH workshop
convened to discuss stigmatisation decided that the word stigma was “too strong” and “one
important consensus of the workshop on stigma was not to use the word except with great care
and in very specific situations” (Gelb, 1980, p. 2). Stigma was then considered to be an
inappropriate term and removed from the title of a number of the workshop proceedings because
“if one is referring to negative attitudes induced by manifestations of psychiatric illness” (Rabkin,
1984, p. 327) this cannot be stigmatisation.

The argument ignored the partial lack of patients’ responsibility for these behaviours, and though
one must understand and acknowledge public fears, the public’s negative attitudes can frequently
be disproportionate to behaviours of patients, attributing a wider range of imperfection to patients
beyond what is deserved by their behaviours, and these attitudes can be directed at them
irrespective of possible variations in their behaviours and other aspects of their personality and
existence, and over-emphasised in order to ensure the self-interest of non-patients. It was such
that the rejection due to patients’ behaviours was taken on board as ‘natural’ without concern that
instances of these ‘justified’ rejections were going to have cumulative effects and were likely to make those behaviours worse; and that as a result of the vicious cycle created, patients were going to deteriorate even further, lose all their possible life opportunities and find themselves in other stigmatised categories such as ‘the unemployed’, ‘outcasts’ and ‘social pariahs’ for which they could be rejected beyond what their behaviours may justify. Besides this, given the work of Farina, Page and several other investigators it seemed likely that labels, in at least a proportion of cases, directly caused stigmatisation.

It took seven years for investigators to start to question the false reassurance built up over a decade that there was little or no stigmatisation and that most was rejection due to patients’ own disturbed behaviour. Link et al (1987) reviewed most of the studies which suggested that behaviour was a significantly more potent indicator of stigmatisation than labels and demonstrated that all behaviour-versus-label studies contained both a serious methodological error and misinterpretation — in that they had all averaged the consequences of labelling which included serious stigmatisation in some cases, provision of benevolent but usually inappropriate help in other cases, and no effect in still other instances. This meant that to assert that the effect of patients’ behaviour in causing stigmatisation is systematically more potent than that of labelling is misguided because a significant proportion of people are indeed subject to serious stigmatisation as a unique effect of labelling. Averaging the various effects of labelling and comparing the averaged-out figure with the effect of behaviour would be both unscientific and unfair as it would put the responsibility for all social stigmatisation directly on the behaviour of the stigmatised and spare society from any responsibility.

Further work re-confirmed previous findings of the existence of stigmatisation towards patients
with mental illness and showed that the label of mental illness can elicit stigmatising behaviour (Piner & Kahle, 1984), false accusations of violent crimes (Sosowsky, 1980, Steadman, 1981), reduced access to housing (Mor et al, 1984, Alisky & Iczkowski, 1990, Page, 1995), access to employment (Bordieri & Drehmer; 1986, Link, 1987) and disrupt interpersonal relationships (Meeks & Murrell, 1994; Sibicky & Dovidio, 1986).

At the same time, it was acknowledged that though patients’ expectations of stigmatisation had some role in their getting stigmatised, this was itself proof of the existence of social stigmatisation internalised by patients. Earlier studies (e.g., Farina et al, 1971) had demonstrated that a person’s ‘knowledge’ that others know about their stigmatised condition, negatively affects their behaviour and success in different areas such as searching jobs. Link et al (1989) presented a modified labelling theory approach to mental disorders stipulating that though labelling would not produce mental disorder, it can lead to negative outcomes for the patients in that the patients internalise societal attitudes towards the illness and become less effective by self-devaluation and/or respond, e.g. by withdrawal, in order to avoid the expected stigmatisation. This would not only reduce their life chances in work, housing and relationships (for example, they would not apply for a job if they expected the employer would reject them) but also put them at risk for the recurrence or prolongation of the illness. As such, patients’ self-devaluation related to expected stigmatisation can have negative consequences for them in addition to any deleterious effect coming directly from enacted social stigmatisation itself.

Stigmatisation seems to swap targets and become more focused on a particular group depending on social, cultural, and economic contingencies. In the 1990's, it became more and more clear that, while in the previous decade or two some were allaying their anxieties by proclaiming that
there was no stigmatisation of mental patients, stigmatisation was actually getting focused more than ever on psychiatric patients. Within the space of three decades huge changes have taken place in the practice of psychiatry, especially in Britain and the United States. With the closure of psychiatric hospitals and discharge of an increasing number of patients into the community, the direct exposure of the public to these patients in the streets and reports of some tragic incidents including homicides involving the latter, stigmatisation has now been re-focused, more than ever, on patients with mental illness. Indeed, the study by Angermeyer et al (1987) suggests that patients treated in modern treatment settings actually perceive more stigmatisation than patients treated in a more traditional institution. There has been no mandate from the public for the above changes in psychiatric practice, and communities may not be capable of showing the understanding and competence that used to be the province of mental health workers in large mental hospitals (Hall et al, 1994).

The special characteristic of this re-direction of populations’ stigmatising tendencies onto patients is its association with the other characteristic of our time: an ever-increasing speed of communication and mass bombardment with images and signals in such a way that, within the space of a few seconds, huge populations are impressed by the same ‘newsworthy’ images of incidents involving a few patients with mental illness. As such, minds are offered suitable commodities, ready-made products manufactured as if on a production chain, providing convenient targets for stigmatising projections. The sum total effects of these new developments may explain why, as the latest reviews such as that by Farina (1998) indicates, social attitudes towards mental illness have not shown improvement over time.

Aware of these sociotemporal developments, the World Psychiatric Association (Sartorius, 1997)
and The Royal College of Psychiatrists in Britain (Crisp, 2000) launched unprecedented and large
scale campaigns of public education against stigmatisation of patients with mental illness. The
present work is done as a contribution to these on-going efforts.

1.3 A Critical Review of Goffman’s Contribution

1.3.1 ‘Stigma’ versus ‘Stigmatisation’

Goffman (1990, original publication, 1963) defines stigma (p. 9) as "the situation of an individual
who is disqualified from full social acceptance" on the basis of their physical deformity, individual
characteristics (such as weak will, domineering or unnatural passions, treacherous and rigid
beliefs, or dishonesty) or those attributes inferred from a record (mental disorder, imprisonment,
addiction, alcoholism, homosexuality, unemployment, suicidal attempts and radical political
behaviour) and tribal stigmata of ethnicity, nationality, religion and social class. Based on the
work of previous authors and his own theoretical developments, Goffman proposed the idea of
a social contribution to stigma. Stigma was conceptualised no more merely as a mark of an
underlying condition or the associated disgrace but as a social process. Goffman’s definition of
stigma includes the process of being socially devalued for having a discrediting condition and
the rest of Goffman’s essay implies that it also includes the process of socially devaluing someone
for having the condition.

Though both Goffman and a number of other authors use the term ‘stigma’ to mean the process
of being socially devalued for having a deeply discrediting condition or the process of socially devaluing someone for having the condition, one can think of *stigmatisation* as a better term for conveying this concept unless the term referred to the ‘mark of disgrace’ itself.

1.3.2 **Stigma as the Defiance of our Assumptions**

According to Goffman, society establishes the set of attributes ordinary and natural for each category of people. “When a stranger comes into our presence...[we make] certain assumptions as to what the individual before us ought to be.” Goffman proposes that we attribute a character to the individual, i.e. “a virtual social identity” on the basis of our own assumptions. As such we “deal with anticipated others without special attention or thought.” (Goffman, 1990, pp. 11-12).

He suggests that the attributes established by society are, to a certain extent, both context-related and role-related. As an example, he mentions the fact that some jobs in the US cause holders without the expected higher education to hide this fact; other jobs can lead some of their holders who have a higher education to conceal the fact because they may be considered as outsiders (p. 13). The assumed attributes are also person-related. For example, people may expect ascetic behaviour from a monk but believe that they themselves do not have to follow the same standards of conduct. In this case, the lack of ascetic behaviour is stigmatising for the monk but not for them. Stigmatisation occurs when “an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim that his other attributes have on us.” (p. 15).

After defining ‘normals’ as those who do not depart from expectations of what a typical category of person should be, Goffman proposes that normals believe that a person with a stigma is not
quite a human so they explain his or her inferiority and dangerousness and exercise a variety of
discriminations in order to reduce his life chances, "sometimes rationalising an animosity on other
differences [other than those leading to the animosity in the first place] (Goffman, 1990, p. 15;
Riesman, 1951).

From reading Goffman one could consider that inasmuch as stigma defies people’s expectations
as to what a given person should be they tend to see the person ‘through’ their stigma rather than
despite or, at least, alongside it. Stigmatisation thus overshadows all other aspects of a person,
downgrading their positive qualities and emphasising their negative points. In their evaluation of
the stigmatised, people do not seem to make an algebraic summation of the negative and positive
qualities of the latter. It is as though stigmatisation would not allow an ‘arithmetic’ addition and
subtraction of positive and negative attributes of a person but acts as an overwhelming power
station minimising beauties, talents and humane attributes in a process we might compare to a
negative geometric progression, and maximising shortcomings and failures in a process similar to
a positive geometric progression. As such stigmatisation gives unjustified dimensions to all real
or imagined failures, detracting attention from the other attributes of the individual, distorting the
sense of proportion, thus leading to errors of judgment and injustice.

1.3.3 The Discourse of Linguistic Intervention

Though society tends to stigmatise, it offers, at the same time, ‘pact’ or ‘contract’ facilities to the
stigmatised. Goffman (1990) proposes the notion of ‘phantom acceptance’ (p. 148) in which the
stigmatised are offered a lip-service normalcy, indeed a ‘phantom normalcy’ in which there is as
If a 'contract' between the stigmatised and the stigmatiser to declare that the former is 'normal' provided that he recognises his 'proper place' — a sort of tacit agreement in which a show of acceptance is put on stage, precarious enough to break down if the stigmatised would not know its limits and wish to draw, in practice, on all the credit he has been accorded theoretically. “He is told that he is like anyone else and that he isn’t.” (p. 150). It is as if there is an invitation to a collusion in which the stigmatised is asked to stop causing pain to the stigmatiser by recounting the story of his misery again and again (indeed, to put the stigmatiser at peace) and in return he would be declared ‘normal’. “He who adheres to the advocated line is said to be mature and to have achieved a good personal adjustment; he who does not follow the line is said to be an impaired person, rigid, defensive, with inadequate resources.” (p. 140). In this context the stigmatised are offered a new burden — that of ‘re-educating the stigmatisers’ or otherwise they will be further stigmatised. In the context of the ‘contract’ “they [stigmatisers] should be tactfully helped to act nicely. Slights, snubs and untactful remarks should not be answered in kind. Either no notice should be taken or the stigmatised individual should make an effort at sympathetic re-education of the normal, showing him, point for point, quietly and with delicacy... ” (p. 141). The implication is that the stigmatised would take care of the feelings of the stigmatisers in a sympathetic, quiet and delicate manner by making jokes about his own stigma, or when the stigma is too shocking, by giving the stigmatiser some space for them to compose themselves, or to show that the stigmatisers’ efforts for normalising him is appreciated. This is indeed a situation in which the stigmatised stand at a distance comfortable for the stigmatiser, still acting as a convenient recipient for the projections of the stigmatisers without having been accorded fundamental acceptance.

From the quotations Goffinan gives to substantiate the above argument, one (p. 140) refers to
proclamations by stigmatisers that words used for stigmatised people are awful because they specify, set apart and are condescending. But, is the whole practice of linguistic intervention just one aspect of the above lip-service normalisation? It is true that one might be taken over by the illusion that the agenda in linguistic intervention is purely a change of designations as a clause of the ‘contract’. Would our task in remedying stigmatisation, in for example schizophrenia, ends summarily upon calling these people, ‘person with schizophrenia’? Is linguistic intervention a clause of the contract to serve stigmatisers or, on the contrary, a means of empowerment, a tool in the service of the stigmatised and advocates for promoting self-questioning and soul-searching enquiries? The response to this question, of course, would depend on which strategy is being served by linguistic tactics and would then entirely depend on whose discourse it is.

One could propose that as stigma defies expectations and obtrudes upon our senses that we give it special prominence in our language. Though representing linguistic intervention as ‘a clause of the pact’, Goffinan warns elsewhere that “we use specific stigma terms such as cripple, bastard or moron in our daily discourse, as a source of metaphor and imagery typically without giving thought to the original meaning.” And then “we tend to impute a wide range of imperfections on the basis of the original one...” (pp. 15-16). He proposes that a “characteristic task of the group representatives is to convince the public to use a softer social label” (p. 37) for the stigmatised. He cites the example of a successful effort by New York League for the Hard of Hearing in eliminating the word ‘deaf’ from their communications, following which New York started to accept the new vocabulary. Goffman’s argument on linguistic intervention as a means of destigmatisation stops here.

It is not surprising that after asserting this important sociolinguistic aspect of stigmatisation,
Goffman himself refers to someone like this: “A multiple sclerotic suggests...” (Goffman, 1990, p. 22); “A cripple [writes]...” (p. 23); “A cripple provides a statement...” (p. 54), “A cripple adds another illustration...” (p. 146), when quoting real people. This might be the way they referred to these people in the 1960's. One might also argue that Goffman wrote without paying special attention to the linguistic implications or meaning of what he wrote. This does not seem to be the case as, elsewhere in the same essay, he spends time arguing, for justified reasons, whether the term ‘visibility’ was better to mean what he meant or ‘perceptibility’ or further than that ‘evidentness’ (p. 65). He would still not feel “safe” in his use of the term ‘visibility’ before distinguishing it from ‘known-about-ness’, ‘obtrusiveness’ and finally ‘perceived focus’! (pp. 65-6).

All intellectuals attempting to achieve an abstract understanding of stigmatisation are, like most people, prone to call the stigmatised as for example a ‘cripple’ while doing justice to an erudite understanding of stigmatisation. This indicates the pervasiveness of the neglect of the linguistic aspects of stigmatisation, to a degree that even a book by an eminent analyst of the subject could not escape using these words “typically without giving thought to the original meaning” (p.15).

Linguistic intervention does not just mean “a softer social label” for the stigmatised but introducing a new discourse of solidarity with the stigmatised, constantly questioning personal attitudes and awareness and sensitivity towards the stigmatised. These issues will be discussed in more detail in the chapter entitled “Routes to De-stigmatisation".
1.3.4 The Normal and the Stigmatised

Goffman proposed that ‘the stigmatised’ have “an undesired differentness” from what we expect. He defined as ‘normals’ “We and those who do not depart negatively from the particular expectation.” (Goffman, 1990, p.15). Such divisions of people to the ‘normal’ and the stigmatised might be interpreted as if there were a strict boundary between the two groups (though, later on, Goffman comes back to this issue: “The most unfortunate of normals is likely to have his half-hidden failing...” (p. 152) ).

In my survey in South Camden & Islington (see chapter on results) the majority of the patients with schizophrenia stigmatised the condition of having schizophrenia, especially in transactions with other patients. Forty per cent denied or were not sure about having an illness and presumably refused to identify with other patients with the same condition. As such, the ‘stigmatised’ could also behave like ‘normals’ and, by definition, be stigmatisers. In this perspective, one could propose that, at least to a certain degree, we are all both stigmatisers and stigmatised in different contexts.

In general, the stigmatised introject the normals’ standards and expectations and become acutely aware of what others see as their stigma yet there are exceptions to this rule. Goffman proposes that it is possible for someone to be stigmatised yet be, for example, protected by identity beliefs of his or her own (such as Orthodox Jews, gypsies and Mennonites) (Goffman, 1990, p. 17) but, the degree to which membership of a particular group such as Orthodox Jews might protect someone against introjecting the prevalent social attitudes about Orthodox Jews is likely to
depend on the psychology of the individual (i.e., their resilience and emotional security) as well
that Goffman does not mention.

1.3.5 The Discredited and the Discreditable

Overtures to the stigmatised person about their stigma may make them feel vulnerable in that they
“can be approached by strangers at will, providing only that they [the strangers] are sympathetic
to the plight of persons of his kind” (Goffman, 1990, p. 28) and the act of approaching them for
some reason related to their stigma may make them feel more exposed than they think they
actually are. Goffman distinguishes the condition of being “discredited” from that of being
“discreditable.” “Does the stigmatised individual assume his differentness is known about already
or is evident on the spot, or does he assume it is neither known about by those present nor
immediately perceivable by them?” (Goffman, 1990, p. 14). He then suggests that the agenda for
the “discredited” is how “to manage tension” in his contacts with stigmatisers, that of the
discreditable is how “to manage information” about himself, i.e., how much to hide his
stigmatising attribute, how, to whom, where and when. (Goffman, 1990, p. 57).

Avoidance by the stigmatised of social contacts with ‘normals’ is proposed by Goffman as another
consequence of stigmatisation. “Lacking the salutary feedback of daily social intercourse with
others, the self-isolate can become suspicious, depressed, hostile, anxious, and bewildered” (p.
24). Goffman then suggests that instead of avoidance, the stigmatised may use bravado inducing
discomfiting reciprocation from others or he can alternate between avoidance, cowering and
bravados. Goffman considers that both the ‘normals’ and the stigmatised arrange life so as to
avoid each other (p. 23), as it is in these encounters they have to face the causes and consequences of stigmatisation (p. 24).

Some patients avoided any contact at the door-to-door survey and also refused to participate when contacted on the phone though some consented to participate after reassurance was given to them, by myself or, if available, a nurse or key worker, about the purpose of the survey. It is likely that one of the reasons for the avoidance was these people’s wish to avoid anything to do with their ‘stigma’ or a surveyor who, by the mere fact of wanting to explore the subject, may be endorsing that it exists and who, himself, can be a potential stigmatiser, especially when they found out that the surveyor was a doctor with all the implications of him representing the medical establishment (with its function of categorising people with diagnoses) though they may also be likely to consider the doctor as someone who, by virtue of working with the stigmatised could be sympathetic to their condition or help them by recommending social benefits or accommodation for them.

The difference of status between the “discredited” and “discreditable” is worthy of further consideration. In my survey, about 10 per cent of the participants had previously been treated by myself. The rest (about 90 per cent) though knowing that the research had been approved by their consultant and/or the hospital, and though approached sensitively, showed, quite understandably, concern that “someone else” or “another doctor” now knew about their condition. The majority needed further reassurance about the confidentiality of their diagnosis more than what one might expect, as though to prevent the possibility of reverting from the status of a “discreditable” to that of a “discredited” person in the eyes of still more people. They were indeed, as much as possible, managing information about themselves. This issue is likely to have fundamental importance in
treatment and recovery of patients with mental illness. For example, those who develop depression or have an addiction to alcohol may remain secretive about their condition for a long time, for fear of getting rejected or losing their job. The same is true of those who start to hear voices or develop delusions in the context of schizophrenia. The transition from the status of a "discreditable" to that of a "discredited" may cause additional conflicts in patients in that the "discredited" position is required for having access to sick benefits.

1.3.6 Stigmatisation and Economy

How do the stigmatised respond to their situation? One option for the stigmatised would be to correct the stigmatised attribute. "A physically deformed person undergoes plastic surgery, a blind person, eye treatment, an illiterate remedial education, a homosexual psychotherapy." (Goffman, 1990, p. 19). But they would then be transformed from someone with a particular blemish to someone with the record of a particular blemish. Goffman then refers to the victimisation of the stigmatised in the sense that, to correct the stigma, they are prepared to go to extremes, spending money to try the offer of whoever claims a cure for their condition. The latter are "fraudulent servers selling speech correction, skin lighteners, body stretchers, youth restorers...cures through faith, and poise in conversation...The extremes the stigmatised can go to correct the stigma shows the painfulness of his situation" (p. 20). The stigmatised also provide a market for more serious journals, pamphlets and books taking the line of their defence. As such, one can see that maintaining stigmatisation has an economic value for certain groups or industries. For example, Western culture presents an ‘underweight’ body shape as ideal for women and stigmatise deviations from it in order to continue to sell heath food, recruit patients for diet clinics.
and consumers for appetite suppressants.

As mentioned above, in the case of people with a diagnosis of schizophrenia there is widespread denial, by patients, of having the stigmatised condition. The result of my survey shows that these patients in general refuse terms such as ‘schizophrenic’ that they consider as offensive. They profess a belief that they are not ill so they would not wish to seek treatment as this would mean endorsing the suggestion that they are ‘mad’. Yet, the argument would not prevent the family who, out of guilt or good will, are likely to seek all sorts of alternative therapies or solicit second opinions, even in other countries, sometimes from those who claim magical cure for the illness.

Campbell (1989) defines tertiary gain as “benefits accruing to someone other than the patient, from the illness of the patient, including other family members, others from the patient’s social system, the physician, etc.” (p. 298). If we consider stigmatisation a social ill, benefits accrued to others from the process are indeed tertiary gain which, in turn, reinforce the process of stigmatisation.

1.3.7 Reclaiming by the Stigmatised of the Lost Value

Goffman suggests that the stigmatised can attempt to correct their condition by making efforts to master activities thought to be beyond them. Citing from the literature, he gives the example of a lame person who learns to swim, play tennis or fly an aeroplane. (Goffman, 1990, p. 20). Later on, he quotes from Henrich & Kriegel’s (1961, p. 19) testimony of a patient with multiple sclerosis, suggesting that the stigmatised might see their suffering as a blessing which teaches
them about life and people or make them see the limitations of ‘normals’. The testimony of the patient says “‘normal’ people can get around, can see, can hear [but that] doesn’t mean that they are seeing or hearing. They can be very blind to things that spoil their happiness, very deaf to the pleas of others for kindness; when I think of them I do not feel any more crippled or disabled than them. Perhaps in some way I can be the means of opening their eyes to the beauties around us; things like a warm handclasp, a voice that is anxious to cheer, a spring breeze, music to listen to, a friendly nod. These people are important to me, and I like to feel that I can help them.”

Goffman also mentions that the stigmatised person may show pride in the special characters of people of his kind. For this purpose, for example some Jewish people may “aggressively interlard their speech with Jewish idioms and accents.” (p. 138). In politicizing the situation of the stigmatised of his own kind the person is, in a sense, reifying the public image of his fellow-stigmatised as a separate group with a real differentness, yet “the next generation of his fellows may greatly profit from his efforts by being more accepted.” (p. 139).

Goffman would not bring the above reactions by the stigmatised under a single concept, i.e., the defence tactic of Reclaiming — attributing positive connotations to bearers of a stigma. For example, to mention the name of someone famous and/or popular and add that he has (or had) the condition concerned is both a reclaiming and a solidarity defence especially if the famous person himself admits to it in public. “Schizophrenics are intelligent”, “They are psychics”, “Schizophrenics are blessed” were the words of some of the respondents in my study, some even mentioning that they preferred to be called ‘schizophrenic’ [because of its ‘positive’ value]. Of course, these assertions are to be taken as protests against the grim reality of their present circumstances and as tactics to boost their self esteem in their difficult struggle with stigmatisation.
One drawback of reclaiming is that some people with experience of schizophrenia may not be satisfied to be described in that way (see below). Another drawback is its being pushed to extremes in that the patient might not seek treatment in order to remain in the condition he has as such re-evaluated as ‘positive.’ Yet self boosting and self elevation by reclaiming is likely to improve the situation of the stigmatised by promoting confidence and dispelling the prevalent discrediting views.

1.3.8 Vicarious Reclaiming by Stigmatisers

Goffman proposes that we “impute some desirable but undesired attributes, often of a supernatural cast, such as ‘sixth sense, or ‘understanding” to the stigmatised (Goffman, 1990, p. 16). He reports from Gowman (1957, p. 198): “Those confronting the blind may have a whole range of beliefs that is anchored in the stereotype. For instance, they may think they are subject to unique judgment, assuming the blinded individual draws on special channels of information unavailable to others.” Goffman reports from another blind woman, “I was asked to endorse a perfume, presumably because being sightless my sense of smell was super-discriminating” (Keitlen & Lobsenz, 1962, p. 10). Regarding evaluation by stigmatisers of the stigmatised person Goffman (1990, p. 26) says elsewhere “His minor accomplishments, he feels, may be assessed as signs of remarkable and noteworthy capacities in the circumstances.”

Goffman mentions that when the stigmatised is placed in a favourable category by others, he will know that “in their hearts the others may be defending him in terms of his stigma...Thus in the stigmatised arises the sense of not knowing what the others present are ‘really’ thinking about
A black social worker appointed as the person in charge of the Emergency Community Mental Health Team in a busy inner London area recently said to me “I know I’ve got this job because of my skin colour.” This response is open to a variety of interpretations, which in its turn, shows, that as Goffinan proposes, how uncertain the stigmatised person could be when faced with a ‘favourable’ act from potential stigmatisers. The social worker was possibly telling me that he had the necessary skills (whether recognised by the panel or not) but that the interview panel selected him out of guilt (of their own or on behalf of their group or class) towards the black in general. Alternatively, he was telling me that he did not have the necessary skills (whether recognised by the panel or not) and had been selected just because of the guilt. By saying that he got the job for his skin colour, he considered it unlikely that the interview panel recognised any skills in him and/or the interview panel offered him the job irrespective of his skin colour. These various and sometimes complex explanations reflect the confusion in the mind of the stigmatised as to possible interpretations of a favourable act towards them.

Here one can distinguish two forms of ‘positive discrimination’: 1) Positive discrimination due to the guilt for personally stigmatising the attribute in question in the past or present. 2) Positive discrimination for philanthropic reasons willingness to own the corresponding public guilt. An interviewer who has not stigmatised the black in his life may still exercise positive discrimination in favour of a black person in an interview not because of guilt related to any personal prejudice but for philanthropical reasons.

Yet, one might choose to disagree with Goffinan on the point of undesirability of positive
attributions by others. There is no proof that the stigmatised would find positively toned comments or attributions necessarily undesired. Though on one hand, as it is likely to be the case with positive discrimination, they would see it as a possible sign of their being compensated for stigmatisation, they would not consider positive evaluations, comments or positive discrimination as necessarily unwanted. In my survey, participants were, in general, sensitive to the purpose of the survey to understand stigma and discrimination, considering the surveyor as a possible advocate. One can propose that though patients might consider efforts at positively valuing them as unwanted at one level, they would, at another level, welcome well-wishing efforts by advocates and those who are likely to promote their cause. From one angle, one could consider others’ reaction in positively valuing the stigmatised as *Vicarious Reclaiming*. What a vicarious reclamer gains for himself in this process is likely to be complex and depends on their individual psychology (see below).

### 1.3.9 Stigmatisers’ Attribution of All Negative Events to the Stigma

Goffman proposes that ‘normals’ would not accord the stigmatised “the respect and regard which the un-contaminated aspects of his social identity have led him...to anticipate receiving.” (Goffman, 1990, p. 19). One of the biases of stigmatisation is that as attention is focused on the stigma, all minor or incidental shortcomings may be taken as an expression of the stigmatised’s differentness. As such, a stigmatised person may be afraid to get involved in sharp interchanges with an employer or partner because of “what a show of emotion might be taken as a sign of” (p. 26). As Dexter (1958) mentions when a stigmatised person get into trouble, it is attributed to his stigma, whereas if someone else gets into a similar trouble it is not regarded as a symptom of any
particular stigma. This is especially applicable to patients with schizophrenia as a lot of their behaviours, actions or reactions could be seen as symptomatic of their illness rather than interpersonal variabilities in personality or reaction to stress that are also seen in other people without schizophrenia.

In my survey, a relative who herself had an experience of schizophrenia wrote to me that frequently when users make a criticism to staff (in hostels or hospitals) which is justified, “it is met with closing ranks. In the end, it is always the users who lose...Due to [this]...many users become refusers, either staying in their rooms or diverting their attention to radio or TV. Anything to escape...As a result, they miss out on the positive benefits of the NHS or other service provision. This means that they remain untreated for longer than is good for them and [so] make their relationships with the services a very expensive one. Those who are confident enough to take on ...are viewed with suspicion and sometimes an us-them battle commences.”

1.3.10 The Use of Stigma as Compensation for Stigmatisation

Goffman suggests that some stigmatised people use their stigma for “secondary gain” or “as an excuse for ill success” (p. 21). Reporting from Baker & Smith (1939, p. 303) he says “It [scar, harelip or misshapen nose] is the ‘hook’ on which the patient has hung all inadequacies, all dissatisfactions, all procrastination and all unpleasant duties of social life, and he has come to depend on it not only as a reasonable escape from competition but as a protection from social responsibility” If one attempts to remove the stigma from the person it is like removing from him “the support of a ‘handicap’ ” which he is “unprepared to cope with.”
In my survey, 25% of patients with schizophrenia preferred to be called ‘schizophrenic’ for various reasons including the fact that in this way “I would be given ‘help’.” This help is likely to be a mixture of treatment, material support and acknowledgement of their privilege to be free from some social responsibility for example work when ill. Yet, the disability of some of these patients is so real that one would hesitate to simply attribute all their social deficits to a wish for ‘gain’. Further, some of what Goffman refers to as “secondary gain” (p. 21) is indeed primary gain. Rycroft (1995, p. 63) defines primary gain as “the freedom from anxiety or conflict achieved” by a symptom (emphasis in the original). As such relief from the conflict about one’s responsibility in one’s failures, or freedom from anxiety about one’s non-achievement are examples of primary gain. Secondary gain is defined as “the practical advantages” to the person of the symptom including “using the symptom to influence or manipulate others.” But what is as important and Goffman would not mention is the extent of primary and secondary gains stigmatisers make though, later on, he briefly, and in passing, refers to “additional functions of stigma” such as “removing...minorities from various avenues of competition” and “narrowing courtship decisions” (p. 165).

One way towards de-stigmatisation is to emphasise the lack of personal responsibility in those illnesses in which the person would not play an active role. All the same, the latter might act as a wrong message to the patient who might interpret it in the service of avoiding any responsibility on the grounds of being innocent in having developed the illness. The problem could possibly be overcome by separating responsibility for having caused the illness from the responsibility to own the illness and make efforts to get better. Even with this distinction, those people with alcohol and drug problems are likely to be more stigmatised (Crisp et al, 2000) as they are considered to contribute to their own stigma.
1.3.11 Stigmatisation and Amplification of Stigmatisers’ Response

Goffman goes on by discussing the discomfort for the stigmatiser “We, normals will find theses situations [encounters with the stigmatised] shaky...We will feel that the stigmatised individual is either too aggressive or too shamefaced, and in either case, too ready to read unintended meanings in our actions” (p. 29). This combined with self-awareness and other-awareness in social interaction between stigmatisers and stigmatised would lead to uneasiness on both sides. We might then treat the stigmatised as “someone better than we feel he might be or someone worse than we feel he probably is” or as a “non-person,...not present at all, as someone of whom ritual notice is to be taken” (p. 30), all these in the context of the discomfort and tension created by the encounter between the stigmatiser and the stigmatised. As such, in social settings, when confronted with a stigmatised person, stigmatisers may perceive themselves as having friendly feelings for the stigmatised or as having aversive feelings towards them.

The above assertions are worthy of further consideration. It seems plausible that the discomfort in social encounters between stigmatisers and stigmatised would signify a state of ambivalence, a combined state of sympathy, uneasiness, anxiety or guilt similar to the one between a victim and an aggressor brought together that may lead to an amplified negative response (avoidance) or an amplified positive response (positive discrimination).

Katz (1981, p. 25) proposes that response amplification may operate not only in social interactions but also with respect to public policy formulations e.g., equal opportunity policies. Yet, one could argue that the latter policies may originate from individuals and groups who are
essentially more liberal and sympathetic in their outlook and whose basic emotional dynamic is not necessarily characterised by ambivalence.

Also, the avoidance by stigmatisers can be interpreted as the stigmatisers' wish to take distance from 'the rubbish basket' in which they have deposited their 'rubbish' originally, but also in order to further prove their 'differentness', 'betterness' or 'otherness'. For example, the tendency of financially prosperous families to move out of poorer neighbourhoods may be seen as their reluctance to encounter the stigmatised and whatever associated with them but also as a means of seeing themselves (or other people seeing them) as 'other'.

1.3.12 The Dilemma of ‘Solidarity vs. Stigmatisation’ vis-à-vis the Fellow Stigmatised

Goffman refers to the comfort that the stigmatised can get associating with those who carry the same stigma: “They can provide the individual with instruction in the tricks of the trade and with a circle of lament to which he can withdraw for moral support and for the comfort of [being accepted] as a person...but he must resign himself to a half-world to do so...he may find that the tales of his fellow-sufferers bore him, and that the whole matter of focusing on atrocity tales, on group superiority, on trickster stories, in short, on the problem, is one of the large penalties for having one.” (Goffman, 1990, pp. 32-33). Goffman then mentions that “being a member of the category [of the stigmatised], an individual may have an increased probability of coming into contact with any other member and even forming a relationship with him as a result.” (p. 36).
Also, Goffman proposes that people “with only a minor differentness find they understand the structure of a situation in which the fully stigmatised are placed—often attributing this sympathy to the profundity of their human nature, instead of to the isomorphism of human situations.” (p. 152). This presupposes that the capacity to empathise is the same in people subjected to an experience seen as a minor version of what the fully stigmatised experience. There is no reason to believe that human beings are the same in their capacity to learn emotionally and to use the emotional awareness empathically. As such there is possibility of contribution from both various degrees of profundity of human nature and the isomorphism of human situations.

With reference to the literature (Palmer, 1958; Landy & Singer, 1961) Goffman reports that patients with mental illness are not very willing to unite and form groups in spite of innocuous titles for the groups. Elsewhere (pp. 130-1) he suggests that the stigmatised have a tendency to “stratify” people who have the same stigma as them. The stigmatised do so according to the obtrusiveness of the discredited attribute in their fellow stigmatised, taking up attitudes to those more stigmatised than them, similar to the attitudes of ‘normals’ towards them. Goffman proposes this to be the reason for the ambivalent identification of the stigmatised with their own groups.

In my survey, “Schizophrenics are my mate” and, in general, the wish to be called “fellow”, “mate” or even “babe” were common (see chapter on patients and relatives’ discourse). These and other similar discourse emphasises the importance of Solidarity as a defence mechanism in the stigmatised. The tendency of the patients to show solidarity with people with the same type of stigma is likely to be the result of feeling threatened by stigmatisers and their need to take action and/or recruit advocates to do so. Advocates are those who are usually recruited from the larger social group of ‘stigmatisers’. Most, if not all advocates are likely to deal with their own or
society's anxiety and guilt about stigmatisation by supporting the stigmatised.

In addition to the reason proposed by Goffman as the tendency of the stigmatised to stigmatise more severely afflicted members of their own group as such undermining solidarity, the wish to deny having the illness might also make the solidarity rather shaky. Those among the stigmatised who would not favour solidarity are likely to be showing their conflict and doubts about having to be 'attached' to or identified with a group of which they have not originally chosen to be a part. Even though groups allow mutual learning, support, development of coping strategies, a social outlet and a platform for political lobbying and campaigns, they are also a disguised form of segregation, an agenda imposed, by intent or in effect, on these patients.

In groups the possibility of patients encountering the out-groups (except carers and advocates) reduces to even less than what it already is. It is also conceivable that someone's association with other people having the same stigma, for example, in hospitals or day centres, by even the mere fact of the person waking into these institutions, acts as an identifier for them suggesting their having a mental illness or being connected with someone who has it. As such one of the dangers of solidarity (and reclaiming) for these patients is the risk of self-exposure to those who are not in the know.

1.3.13 Adaptation of the Stigmatised to Their Own Stigma

According to Goffman (1990) there are four situations for the stigmatised in which they realise their stigmatised condition. The first is the situation of someone with an inherited or congenital
condition who comes to know about their stigma and the corresponding social attitude from the start. The second situation arises in a similar case but the stigmatised is protected by the family or guardians from the knowledge of the social attitudes till later when he goes to boarding school, starts dating or looks for a job and discovers the extent of the stigmatising social attitudes towards their condition. In a third situation the person will develop a stigmatised condition such as a physical disability after he himself has incorporated the stigmatising social attitudes. The fourth situation is that of someone brought up in a foreign or alien environment who now enters a society which considers its own way of life as the only valid one.

The third situation is relevant to patients with schizophrenia who develop the illness later in life. After realising they have developed the condition, they already expect and feel the stigmatisation without having necessarily experienced any enacted stigmatisation. They are likely to think themselves 'justified' in their feeling stigmatised as justification for them is what other people think of them and the 'evidence' of what others think would be the attitude (attributed stigmatisation) they themselves shared with stigmatisers before they developed the illness (attitudes which they may still continue to hold about 'schizophrenics'). Subsequent episodes of enacted stigmatisation would then be interpreted as further evidence of others' attributed stigmatisation and thus perpetuate any expected and felt stigmatisation.

1.3.14 The Visibility of Stigma

The visibility of a stigmatised condition is its evidentness (Goffman, 1990). For example a disfigured face is evident in ordinary social encounters. 'Know-about-ness' has to do with
someone's previous knowledge of the attribute in the stigmatised or previous personal encounter with the stigmatised. 'Obtrusiveness’ is the degree to which it interferes with smooth social interaction. For example, facial disfigurement would be much more obtrusive than disfigurement of the feet. ‘Perceived focus’ is the social situation on which stigma is focused. Stigmatisers may stigmatise the person with facial deformity as a potential partner but not in his or her capacity as a solitary task performer (Goffman, 1990, pp. 65-6).

Relationships, intimate or casual, become a danger as the likelihood of the stigma being known about would increase by closeness and even small talk (Goffman, 1990, p. 108). In these circumstances, people may feel fearful that in the case of a discovery they would be “doubly exposed: first, in their differentness and secondly in their dishonesty and untrustworthiness” (p. 118). It is likely that the fear of being discovered as the bearer of the stigma can cause anxiety in the stigmatised “in living a life that can be collapsed at any moment.” (p. 109). As Sullivan (1956, p. 145) mentions “The fear that others can disrespect a person because of something he shows means that he is always insecure in his contact with other people; and this insecurity arises, not from mysterious and somewhat disguised sources, as a great deal of our anxiety does, but from something which he knows he cannot fix.” The act of hiding discreditable information about self increases the fear of being discovered and interferes with inter-personal behaviour (Pennebaker, 1997, Smart & Wegner, 1999). The discreditable person has to pretend not hearing offensive comments or insulting jokes about his fellow stigmatised and even laugh with others when hearing them. This may lead to feelings of falseness, guilt and disloyalty towards the fellow stigmatised and cause further self-devaluation. The stigmatised has to “be alive to the social situation as a scanner of possibilities...since new contingencies always arise, making former concealing devices inadequate” (Goffman, 1990, p. 110). As such the stigmatised have to
calculate and scan, measure and assess, pretend and lie, ignore and avoid, deceive and play roles in order to preserve his secret.

The notions of visibility, known-about-ness, obtrusiveness and perceived focus of a stigmatising attribute can be applied to patients with a diagnosis of schizophrenia and will be discussed in the next chapter on the stigmatisation of schizophrenia.

1.3.15 Deviancy and Stigmatisation

Goffman defines as deviant “any individual member [of society] who does not adhere to its norms” (Goffman, 1990, p. 167). Deviance is then any behaviour that violates social norms (Horwitz, 1982). Examples of deviants are eccentrics (usually taking their deviant stance individually) or cultists (who take a collective deviant stance) and social deviants (people with addictions, gypsies, prostitutes). Though a considerable variety of deviants are likely to be stigmatised, there are categories of deviants who are not stigmatised, for example a priest who lives a moral life which is more moral than normal (though for that reason, he is not considered a ‘deviant’ in the strict sense of the term). Another example would be someone physically sick who “deviates from performance standards without its being taken as a reflection on him or on his relation to the group.” (Goffman, 1990, p. 168). Other examples are “political radicals” and “the travelling rich” who are not necessarily stigmatised. Social deviants often feel that they are better than normals “obtaining not only sympathy [from the ‘normals’] but also recruits.” (p. 172).
The extent to which Goffman goes in enumerating a list of deviants is, to some extent, stigmatising (though not surprising as he agrees that we all stigmatise). He includes in his list of deviants along with “prostitutes”, “criminals” and “drug addicts” such people as “jazz musicians, show people and carnival workers” (p. 170). He then adds that “..they show open disrespect for their betters; they lack piety; they represent failure in the motivational schemes of society” though, earlier on, he suggests that these people are “perceived as failing to use available opportunities for advancement in the various approved runways of life.” (p. 171). (emphasis added).

The relation between deviancy and stigma is worthy of further consideration. Some of the examples Goffman gives of non-stigmatised deviants seem in general unjustified. For example, “someone married to a mean and selfish mate” that Goffman considers as an example of deviants “who are not stigmatised at all” (Goffman, 1990, p. 174) is likely to be stigmatised by association and contingency. As such, the concept of deviancy and stigmatisation are close and interwoven and there are considerable areas of overlap. Nevertheless, one can think of clear examples where a deviant is not necessarily stigmatised for his deviancy and, on the contrary, valued. A person who spends most of his life exploring Antarctica as his sole hobby, with ardent interest, generally away from the civilised society with its routine of work and family, can be considered a deviant but is likely not to be stigmatised for his deviancy. He is not likely to be in competition with members of larger society, he is not a danger to people living elsewhere, he is not involved in decisions regarding courtship so he is not a genetic threat to anyone, and he is geographically removed and inconsequential to other people. Yet, for his lifestyle devoted to snow humps and glaciers he is a ‘deviant.’
1.3.16 The Mechanism of Spoiling of Identity

Goffman presumes that the stigmatisation spoils the stigmatised person’s social identity “cutting him off from society and from himself.” He is then a “discredited person facing an unaccepting world.” (Goffman, 1990, p. 31). Goffman does not explain in any detail how the attribution could spoil the identity of the stigmatised, outside emphasising the tension to which the stigmatised is exposed in stigmatisation management or information management. What is sure is that whatever the stigmatised choose to do, their constant preoccupation with what they should do or their efforts to fight with stigmatisers is an agenda imposed on them. There is at best a shift (to cope with the new circumstances) and at worst a spoiling of their identity. It would be interesting to explore, at least on a theoretical level, how someone’s identity can be spoilt by stigmatisation. This is going to be attempted in the next section.

1.4 A Psychoanalytic Perspective on Stigmatisation

It is likely that people behave more or less along the line of what is projected onto them which, when introjected, spoils their identity. There is no systematic work on stigmatisation in psychoanalytic theory and those who occasionally consider stigmatisation along psychoanalytic lines would propose the defence mechanism of projection as its tool. Here one could attempt to apply the psychoanalytic theory and, as an example, Kleinian theory in order to better understand stigmatisation. According to Kleinian theory, in projective identification, the person splits part of his self (and an associated impulse) in his psychic space, disowns it, and then identifies it with someone’s else’s character. The process is unconscious though ‘identification’ refers to the
Kleinians emphasise the psychic reality in the mind of the projector and do not busy themselves with finding out whether the projectee actually possesses the trait or not or otherwise deserves the projection or not. Goffman’s theory does not pay attention to stigmatisers’ active choice of people to project stereotypic images onto them. Indeed, the projector usually chooses those who are ‘justifiable recipients’ or suitable targets for the projection but indeed the objective presence of an objectionable trait in others would not exclude its presence in the stigmatiser. This means that the stigmatiser can objectively recognise a certain trait in the stigmatised while himself possessing that trait. Someone who says that Hitler was cruel is probably consensually right but can be cruel himself and uses the cruelty of Hitler as a means of forgetting his own cruelty. On the other hand, the stigmatised might not have the claimed objectionable attribute either because the stigmatiser’s mind works at a level which is ‘psychotic’ and projects chaotically at anyone close at hand, or that the stigmatiser uses gossip or misinformed assertion to discredit the person he stigmatises for reasons such as rivalry (for affection, respect or resources).

Projective identification is a bilateral process. Not only does the stigmatiser identify a trait in others (that the stigmatiser himself may possess) but the stigmatised too feel some attribution thrown onto him. He has too choices: either to go along with it and behave as if he were the person who had the stigma projected, or to resist the stigmatisation by rejecting the projection saying or acting in a way as to declare “No. I am not that.” According to the Kleinian theory, people tend to behave in conformity with the image projected onto them.

There is experimental evidence for the theory (Sherif, 1937; Asch, 1951; Milgram, 1964;
Rosenthal & Jacobson, 1968; Synder et al, 1977). For example if men speaking on the phone to woman they do not know are told that the women are attractive, they are likely to project the schema of attractiveness on the women, speaking to them in a friendlier and warmer way, and as a result, elicit more humorous and warmer (i.e, socially attractive) responses from them, irrespective of the actual attractiveness of the women. The contrary would be the case if the men are told the women concerned are unattractive (Synder et al, 1977). This suggests that people tend to show behaviours compatible with the image we project onto them. A teacher’s projection of a trait on a student would actually influence the behaviour of the student. So that if a teacher communicates in such a way that implies the projection of the idea that a certain student is dull, the latter tends to do worse at school and vice versa (Rosenthal & Jacobson, 1968). It is likely that when one attributes madness to others, they start behaving more like a ‘mad’ person especially as this would at least confers them the ‘advantages’ of being ‘mad’, now that all the associated disadvantages have already been forced onto them.

Another reason why the stigmatised may yield to the idea projected is likely to be the fact that he may already be replete with self-doubt that he resisted until now. If he does not actually have the attribute projected the possibility of him yielding to the idea is likely to depend on the social pressure and factors such as the power of the gossip made as a result of defamation or misrepresentation of his character. Even when there is no collective pressure on him, he might always suppose that there may be traits within him he is unaware of or wonders whether he acts in a way that makes a wrong impression on others. He senses his reflected self-concept and realizes that there is a concrete image of him in the mind of the other as ‘a third person’ or for that matter, ‘non-person’ he has to ‘kill’ in order to prove his innocence, authenticity and real identity. Thus there is work waiting for him to do. He has to make efforts, devise ways of approaching,
behaving or communicating which might persuade, if possible at all, the stigmatiser that he, the stigmatised, is not who the stigmatiser believes him to be. Depending on the degree of projection and motivation for stigmatisation this can be an onerous task. He has then to fight and needs to choose whether he is prepared to pay the cost or alternatively relinquish the effort. His work is going to be more difficult as his efforts to clear the wrong impression might be seen as him denying the 'stigma' or wanting to appear to be what he is not. The responses and reactions of others make his life more 'determined' along the lines chosen by others, imposing an identity on him that he has not chosen and restrict him in what they suppose or 'know' him to be. In these circumstances, he is likely to relinquish any effort, yield to the proffered identity and behave in conformity with it. Alternatively he may choose to resist the projection and, to do so, he is likely to need a great deal of inner strength in order to stand up and say “No, I am not that,” imposing on others his own version of his identity — what he believes he is.

Here, one should emphasise that though the use of projective identification as a tool to comprehend stigmatisation is useful, at least in certain cases, the stigmatiser may choose to attribute some objectionable character to the person stigmatised, not from one of his own characters but from an inventory of attributes objectionable to society and not always for getting rid of one of his own unwanted characters but for downgrading a rival in the context of an economic competition.

A second psychoanalytic interpretation of stigmatisation, along Lacanian line of thought, will be given in the chapter on language, discourse and stigmatisation.
CHAPTER II

A UNITARY THEORY OF STIGMATISATION: THE
PRINCIPLE OF SELF-INTEREST
2.1 The Development of a New Concept of Stigma

2.1.1 Introduction

Stigmatisation is a multifaceted model that, because of its complexity, cannot be easily defined. To do justice to this multivarious concept, one has to present a definition with precise inclusion and exclusion criteria. The following has been devised for the purpose of this study and future research. This definition of stigmatisation retains one concept from Goffman (1963) - that stigmatisation is deeply devaluing and imputes a wide range of imperfections. Nevertheless, Goffman's concept of stigma neither excludes instances of non-stigmatisation nor incorporates the aetiology of stigmatisation.

The first concept included in this definition in that of self-devaluation or self-referential ideations due to mental illness such as a depressive disorder or psychosis which are not necessarily generated, at least in their entirety, by an internalisation of social stigmatisation though they are likely to resonate with social stigmatisation. As such the definition of stigmatisation is intended to be more objective and focused than the prevalent sociological concept of stigmatisation which would not consider the mental state.

The second concept introduced by this definition is that the ultimate cause of all stigmatisation is pursuit of self-interest. While not all cases of pursuit of self-interest cause stigmatisation, all stigmatisation is due to seeking of self-interest, safety, security and self-elevation.
2.1.2 An Operational Definition of Stigmatisation

A) Stigmatisation occurs when self-interest causes people to discredit economic, ethnic, religious, political and social targets who have, might have or are rumoured to have an 'objectionable' attribute or a 'discredited' membership.

B) As the targets’ possession of an objectionable membership or attribute can neither be always verified nor it is always cost-effective to do so, a larger group than those having in effect the given membership or attribute — such as posing an actual, objective threat — are stigmatised on the basis of a mere possibility, however small, that they for example pose such a threat. The mere possibility of a threat or having an objectionable attribute or membership is then used as adequate justification for stigmatisation for lack of a better indicator.

C) The target is objectified by being allocated to a class and attributed a wide range of imperfections beyond what the attribute or membership of the group justifies and with little or no consideration of personal variations or other aspects of their individuality.

D) There is evidence of actual or potential, enacted discrimination (including rejection, segregation, distancing or avoidance) towards the target or towards their symbolic representations or evocations, such that they are not seen as possessing equal potential, status, rights, social responsibilities or social participation beyond what having or the possibility of having the 'objectionable' trait or membership justifies.
E) Self-stigmatisation is the internalisation of social stigmatisation based on prior self-interest. If self-devaluation is found in the person concerned, it must not be considered as necessarily representing stigmatisation, at least in its entirety, should it be the result of a depressive disorder with its inherent self-devaluing component which is not necessarily due to social stigmatisation, though it may well resonate with it.

F) Perception of devaluation towards self must not be considered as totally or at all perceiving social stigmatisation if it is purely the result of a persecutory delusion generated only partly or not generated at all by social stigmatisation though it may well resonate with it.

2.1.3 Aspects of Stigmatisation

Stigmatisation is a multi-faceted and complex model of social response. Scambler (1989) distinguishes two aspects of stigmatisation: felt stigmatisation (subjective fear and shame at having a stigmatised condition) and enacted stigmatisation (observable episodes of discrimination due to the stigmatised condition).

Here one can propose to define three more aspects: Attributed, Expected and Perceived Stigmatisation.

Attributed Stigmatisation is the process of socially devaluing self or others for having a given condition. An example is the stigmatisation, by a racist, of the condition of being black whether
the stigmatiser is black or not.

**Perceived Stigmatisation** is the stigmatisation that one perceives in an act, attitude, situation, emotion or expression towards oneself or others.

**Expected Stigmatization** is expecting oneself and/or others to be discredited for having a given condition. This is not always associated with personally enacting stigmatisation. An example is the Orthodox Jew who would not stigmatise the condition of being an Orthodox Jew (no attributed stigmatisation) while expecting the stigmatisation from other people. Another example is the liberal person who does not stigmatise the black (no attributed stigmatisation) but is aware of stigmatisation by racists (expected stigmatisation).

Expected stigmatisation is then the awareness of the possibility of stigmatisation by certain people of a given condition in self and/or in others. Even though what seems to be significant is the effect that 'patienthood' has on reducing opportunities for work and accommodation, together with relative poverty and experienced hardship (partly the effects of enacted stigmatisation), similar suffering can result from felt, perceived or expected stigmatisation. The 'awareness' of a person of any possible stigmatising attitudes to them by others (expected stigmatisation) puts them in a position in which they feel vulnerable to what others may choose to do (enacted stigmatisation) whether in practice they do it or not. Research has demonstrated that people's knowledge that someone knows about their stigmatised condition, negatively affects their behaviour and success in different areas such as obtaining a job (Farina et al, 1971; Link et al, 1989).
2.2 The Origins of Stigmatisation

2.2.1 Constitutional origins of stigmatisation

This is an area in the study of stigmatisation which has not until now been systematised into a distinct domain. It is sobering to notice that, in some respects, our mind is made up in such a way as to stigmatise. Constitutional factors, which are indeed biological, interfere with the capacity for 'proper' social perception and information processing. For example, after coming across someone disturbed with acute schizophrenia, are people more likely to consider "He was dishevelled and odd" or "He was fit and fast" (when the person has all the four attributes)? The intuitive response is going to be that people are more likely to selectively consider that the person was dishevelled and odd. Research supports this hypothesis. It has been argued that the mind weights negative evaluations in preference to positive ones (Kanouse & Hanson, 1972). Also, the mind, when overloaded with data (as is perhaps characteristic of our epoch) is likely to treat repeated examples of the behaviour of a single individual as independent instances of the behaviour of their group (Rothbart et al, 1978). The implication for psychiatry is daunting. Repeated episodes of violence by one or a few people with mental illness are likely to be interpreted as independent episodes of violence committed by the category of patients with mental illness. Further, the mind, attempting to cope with the influx of data, categorises objects and events in order to economise on resources of memory and perception (Macrae et al, 1994a) and so gains by saving on cognitive efforts. This would lead to imprecision and gross generalisation which are among the cores of stigmatisation. The simplification free up cognitive resources for use in other tasks, providing us with quick-and-easy stereotypes at the expense of sophistication.
and depth.

The mind also tends to associate negative events (which are rarer than neutral and positive events) with other 'rarer' events or objects for example with members of minority groups (themselves less numerous and more distinctive) as opposed to the majority (Hamilton & Gifford, 1976; Hamilton & Sherman, 1989; Stroessner et al, 1993). This tendency comes from the process of distinctiveness by rarity and association of distinct events and objects. So the mind associates cases of 'crime' (which are, by nature, rarer and so more distinctive than instances of 'non-crime') with minorities rather than with majorities. The implications of these findings are fundamentally disturbing and have pivotal significance for making sense of stigmatisation of minorities.

The constitutional factors are instruments in the service of the pursuit of self-interest (Fig. 2.1). They are likely to lead to judgments unfair on others yet they can be adaptive by the very small probability of protection they could offer (for example, in some circumstances one might avoid danger by preferentially weighting negative evaluations about people).
Fig. 2.1 Principle of Self-interest, Structure of Stigmatisation and Potential Targets of Anti-Stigmatisation Campaigns (*)
2.2.2 Psychological Origins of Stigmatisation

Social panic, fostered by the mass media, works by downloading diffuse anxieties that exist in any society towards targets such as 'the mentally ill'. These deeper anxieties expressed towards social scapegoats legitimises repressive measures to contain them. Also, exaggerating differences between in-group and out-groups tend to obscure dissensions within the in-group (Townsend, 1979) promoting the in-group cohesion and ultimately serving the self-interest of members of the in-group.

Designations can acquire invalidating attributes through systematic association with unpleasant or threatening circumstances (Staats & Staats, 1958) as in media publicity over violence by patients with mental illness. Any mental disorder tending to threaten social order would be negatively sanctioned and is likely to be stigmatised by those persons who may, do or have to confront it. The association between the threatening mental illness and the negative sanctions can be reflected in the emotionally loaded variations of terms used to designate patients with mental disorders. If we despise a symbol, e.g., a linguistic representation, and a person bears that symbol we are likely to react to that person as a personification of the symbol we have learned to despise. The response, typically fear, suspicion or disgust, can then act as an aversive factor leading to avoidance. The same is true when we are faced with the stigmatised themselves as we are likely to feel uncomfortable, by the mere fact that, e.g., bizarre behaviour or facial disfigurement could challenge our norms, values and expectations. To reduce the tension, we are likely to avoid the stigmatised, which, in behavioural terms (Bandura, 1977) means reduction in tension and thus psychological gain. As such, the stigmatiser draws primary gain by reducing his anxiety, getting
powerfully reinforced in his avoiding the stigmatised or their symbolic representations on each new occasion. As such stigmatisation works as a vicious cycle, likely to get worse as we get relieved of our anxiety, again and again, by avoiding the stigmatised.

To deal with any possible feelings of guilt this may cause we may resort to rationalisations such as the Just World Hypothesis (Lerner & Miller, 1978; Lerner, 1980). The idea that someone can experience illness or injury without being responsible, threatens us and we need reassurance that the same fate is not going to befall us. Some of us may then propose that the stigmatised or their parents have done something wrong and are being punished deservedly for their sins. This allows the pursuit of psychological self-interest without our feeling guilty.

Promoting the idea that psychiatric patients have ‘free will’ and resorting to the concept of self-infliction, e.g., in addictions found in surveys of public opinion (Crisp et al, 2000; Department of Health, 1999) indeed serve as devices to allay communities’ guilt and are typical applications of the Just World hypothesis. Though the form of this discourse is identical to that of a conscientious doctor, social worker or family member who wish to induce awareness and ownership in those having addictive problems, the motivating factors for these discourses are not identical. The ‘reasonable’ form of the discourse must not divert our attention from the reason-d’être of a discourse because discourses identical in form can serve diagonally opposed purposes as will be described in the chapter on language, discourse and stigmatisation. The public faced with suggestions that they might be discriminating against patients with mental illness tend to download the blame on those patients who can be ‘reasonably’ proposed to have ‘brought about’ their own condition. This rationalisation, though containing an element of truth, also serves some affective purpose for the public — reducing the burden of their guilt, i.e., psychological gain, and locating
at least some of the responsibility in others. This rationalisation includes a crude judgment which would not consider the situational, socioeconomic and biological contributions to addictions. And though such ideas can have some effect by eliciting some sense of responsibility in the stigmatised (Johns, 2000), it is easy to see that it has not been necessarily devised by the public for this purpose. By the same token, a potential stigmatiser tends, as much as possible, to choose to stigmatise those who, at times, actually possess the stigmatised trait, for example those who are actually violent, in order to have strong justification for feeding the need to stigmatise.

What makes the judgment of ‘self-infliction’ an instance of stigmatisation is that this allocation of responsibility is usually associated with a rather systematised attribution of dangerousness, evilness, inferiority or lack of intelligence and can be inevitably exploited psychologically by those promoting the idea of self-infliction. This implies that the ‘rational’ argument can be associated with attributing a wider range of imperfection to these patients than is deserved by their behaviours and over-emphasised in order to ensure the self-interest of non-patients. These ‘justified’ rejections are stigmatising for still another reason: They are likely to block any positive help that neighbourhood could offer these patients which could help prevent their further objectification and deterioration. As a result of the vicious cycle created, patients are going to lose their possible remaining life opportunities ever more easily and decline even further.

We all have wishes, desires, likes and dislikes and tend to use others as recipients for the roles we think they are taking or we want them to take in the scenario we imagine for the world around us. The projection, projective identification, attribution, or whatever else one chose to call it on the basis of one’s theoretical stance, is likely to comfort the anxiety about not knowing a ‘stranger’ through turning them into ‘someone the stigmatiser knows to a certain degree’. As
such the stigmatiser is likely to feel more 'in control' and 'less threatened' by the unknown. At the same time, the stigmatiser takes distance from what might be discomforting in their own character. So, they disown that part of themselves and attribute it to the stigmatised. In this process they get pleasure and satisfaction by 'proving' themselves 'better' than the stigmatised.

In the case of patients with schizophrenia, they are, at times, severely affected to a degree that most aspects of their mental functioning can be significantly deteriorated. Some even do not respond to medications and though at times they would seem rather recovered, the underlying pathology might still dominate their mental functioning. In these situations it might be 'technically' more accurate to refer to them as 'schizophrenics' but this is likely to be deployed by stigmatisers to channel out their anxieties about their own sanity. As such, the objectivity of the severe illness would be inevitably exploited by a wish to distance oneself from one's own shortcomings and faults without acknowledging that no one is perfect or sane in all moments of their lives.

Humans, though generally not endorsing misfortune for others, are willing to use 'unfortunate others' to feel happier about their own situation. People in groups in which reward is equally distributed are less satisfied in comparison with people in groups that include an unfortunate person, though they are likely to acknowledge the unfairness of the situation (Brickman, 1975). Further, people subjected to threats, failures and frustrations of everyday life and those with low self-esteem tend to derogate others in order to bolster their self-esteem and feelings of well-being (Gibbons & Gerard, 1989; Wills, 1981). On the contrary, people with higher 'intelligence' and greater self esteem (Nunnally, 1961) and so more robust personalities are more likely to hold positive attitudes towards patients with mental illness probably because they would not need to
derogate the mentally ill in order to feel intelligent or positive about themselves. This suggests that the greatest variability in the tendency to stigmatise is likely to emanate from individual differences in the tendency to pursue self-interest systematically.

In perceiving “the other person” as “bad” the stigmatiser is likely to feel better about himself. His discourse is likely to consist of “They are bad, so I am OK.” The phenomenon is similar to someone feeling eloquent when s/he considers another as inarticulate, or feeling beautiful when s/he considers someone else as ugly. The allocation of ugliness or inarticulateness to the other provides the stigmatiser with relative self-glorification and helps him downplay his own negative attributes by detracting full attention or awareness from self to the discredited attribute of the other. As such, the stigmatiser ‘benefits’ from the presence of the stigmatised as the latter provide him with examples he would consider as ‘worse than him’ in order to redress the balance. So stigmatisation, even when it relates to an objective deficiency in the other, would somehow serve stigmatisers and pays them psychological dividends.

2.2.3 Economic Origins of Stigmatisation

The stigmatiser’s discourse has economic aspects as well. “I must avoid danger to survive and compete.” To increase one’s chance of access to resources, stigmatisation of the rivals is used as a weapon in socioeconomic competition (Sherif et al, 1961; Hatfield et al, 1978). The latter is likely to be more intense in more competitive, self-seeking societies, moderated in turn by the ease of availability of resources. Hovland & Sears (1940) demonstrated that the number of lynchings of blacks in the US between 1882 and 1930 varied in line with the economic indices
such as the value of cotton. As the economy worsened more blacks were lynched, as it became better, fewer blacks were lynched. Hepworth & West (1988) confirmed the above findings using more representative economic indices. Of course the relationship between the price of cotton and lynching is a correlation but what could be the superordinate cause bringing about their co-variation? The likely interpretation is that competition for scarce economic resources intensifies hatred and stigmatisation. As such, these disturbing findings are likely to relate to self-interest. In circumstances where the ‘aggression’ inherent in wanting to push someone else back, the ‘aggression’ of stigmatisation, is such that “benevolent social action” has to be “designed to soften and ameliorate” it (Goffman, 1990, p. 15), the pervasiveness of stigma and its inherence in human character make one pause and reflect. Goffman alludes to a world in which our good wishes and tendency to protect the weak, the elderly or needy people are themselves indicators of presence of something else we want ‘to compensate for’ — stigmatisation by us of others. A world in which charitable actions, altruism and benevolent social work are “designed” to soften the effect of our ‘aggression’ is a world in which we resort to ‘morality’ to rescue ourselves from the results of one’s tendency to ‘slaughter’ the rivals. These days the expression of discrimination may not be lynching. A football team may accuse another team’s members of drug abuse or disgraceful social behaviour. Here the former is not necessarily projecting one of his own attributes onto the stigmatised but one out of a list of socially objectionable attributes.

It is probable that, among other factors, the economic decline in Germany in the decades before the World War II led to the stigmatisation and violent extermination of Jews. Also, one can argue that the relative economic affluence in the West from 1960's to 1990s may have promoted de-stigmatisation campaigns.
2.2.4 Evolutionary Origins of Stigmatisation

Stigmatisation as a tactic for survival and reproduction is a discourse implying a genetic push towards ‘discrimination’. One can conceptualise the idea as suggesting that genes make humans and animals *discriminate* in order to avoid dangers including natural dangers (snakes, heights, darkness), illness danger (avoiding rotten food, avoiding those having a contagious disease), mechanical danger (avoiding falling objects, avoiding those who pose a physical threat to others) and ideological danger (avoiding ‘deviants’, non-conformists and ‘psychopaths’) (Buss, 1999). Those who are poor bets genetically (carrying genes for a disease), reproductively (unattractive, disabled, resourceless), in terms of security (criminals, ‘psychopaths’, exploiters, cheaters) (Buss, 1999; Gilbert, 2000) and in terms of survival (‘social parasites’, people infected with contagious diseases; people exacting resources) are avoided and there is competition with potential rivals for resources, all in the service of genetic interest. Thus those potentially violent because of an underlying mental illness; those likely to carry genes for a mental disorder, e.g., manic depressive illness and those unable to control resources such as people actively suffering from depression are stigmatised for the genetic interest of the stigmatisers.

2.3 A Unitary Theory of Stigmatisation

Can it be thought improbable, seeing that different origins of stigmatisation point to the individual’s seeking of personal gain as their pivotal motivation, that the fundamental basis of all stigmatisation is *Pursuit of Self-interest*? Can we doubt given the fact that self-interest presents as the ultimate feature of stigmatisation in all domains — constitutional, psychological, economic
and evolutionary — that when there is no pursuit of self-interest there will be no stigmatisation. In other words, so long as we pursue self-interest we have to face the consequences of our stigmatising others.

Stigmatisation essentially implies self-protection, self-seeking behaviour and sometimes selfishness. It is why delving into it makes people uncomfortable as it refers to a fundamental ‘bias’ whose awareness may give rise to guilt. Yet, this would not necessarily prevent stigmatisation as the latter has a protective function for whoever stigmatises. For example, by avoiding travelling on a train driven by someone known to have epilepsy the stigmatiser protects himself from the possibility, however slight in a well controlled epilepsy, of the driver having an accident causing harm to him. By avoiding the population of patients who have schizophrenia, a stigmatiser avoids the possibility, however much it is, of being subjected to disturbed behaviour. The banker who would not give loans to those in lower economic echelons would protect his own investment and employment. A football team may accuse another team’s members of drug abuse or disgraceful social behaviour in order to promote their own popularity. The stigmatisers would avoid a priest who preaches puritanism while himself allegedly getting involved in a lurid affair, in order to protect themselves and/or their family from the possibility of being exposed to the priest’s dishonesty. A person who would not wish to marry someone with manic depressive illness keeps the statistical risk of his children developing the disease.

Stigmatisation is thus a protective device for stigmatisers and unfair on the stigmatised as he may not be the one who causes harm or he may just be the victim of a rumour. The relentless character of stigmatisation comes from this very fact that it could be protective for stigmatisers so it happens despite the fact that the stigmatised may not, in reality, possess the stigmatising attribute.
or could have other traits or attributes that claim recognition and/or respect. In the present state of civilisation, a society without any stigmatisation is not imaginable yet a society which continuously reflects on the degree, reasons and varieties of its stigmatisation is more likely to be a considerate society. One does not need to go back more than sixty years to observe the consequences of unbridled stigmatisation in the heart of Europe. Allport (1954, p. 15) mentions that Hitler’s ideas “led Germans to avoid their Jewish neighbours and erstwhile friends. This preparation made it easier to enact the Nürnberg laws of discrimination which, in turn, made the subsequent burning of synagogues and street attacks upon Jews seem natural. The final step in the macabre progression was the ovens at Auschwitz.”

Not only do the stigmatisers draw primary gain through relief of anxiety by avoidance and projection, they also draw secondary benefits from stigmatisation by avoiding whatever possible danger, loss or victimisation and by increasing their chances of economic prosperity and survival. Primary (psychological) and secondary (economic) gains are likely to constitute the mainstay of stigmatisation.

What is the origin of self-interest itself? Is it biological or acquired? Is it innate or learned? Perhaps a mixture of all. ‘Constitutional, psychological, economic and evolutionary’ the paradigm I deployed for the purpose of better understanding, for the sake of having more channels to delve into a single phenomenon. In practice, all the components of this paradigm intermingle, overlap, work together and inter-relate extensively. This means that it is not the case that stigmatisation is either economic or genetic, psychological or constitutional. It is all or most at the same time inasmuch as stigmatisation can cover all these domains simultaneously. While a stigmatising act could be facilitated by a constitutional factor, it is likely to be, at the same time, deployed for
socioeconomic competition, provide psychological gain and satisfy an evolutionary self-interest. For example, in a decision to reject a partner whose control of resources is poor, the mind may be spontaneously weighting negative attributions more than positive ones, the allocation of badness and avoidance of another can provide psychological gain, the decision can yield benefits in socioeconomic competition and finally the evolutionary need of distancing “poor reproductive bets” can be satisfied at the same time. As another example, the choice of a certain political ideology favouring strict division between social groups, classes and individuals is likely to respond, among others, to a psychological need such as the need to dominate, distance, control or coerce as opposed to the wish to share, promote compassion, equality and interdependence. This is likely to involve the mind categorising and labelling, satisfy economic profits of the protagonists by a differential system of social privileges as well as respond to a primitive evolutionary urge.

My aim in differentiating origins of stigmatisation into domains has been to look at the range of tools for intervention that each of these fields of enquiry brings to bear. I have tried to be more reductionistic for the purpose of acquiring more dimensions and more devices. The reductionism involved in using different branches of knowledge to study the same phenomenon provides us with more aspects, angles of views and dimensions; more pieces of a jigsaw puzzle for delineating the origin of a phenomenon, and more means and devices for intervention to remedy any aberration. For example, constitutional factors are of course biological and possibly evolutionary yet I have considered them separately as they involve responses which are rather more ‘primitive’, ‘vegetative’, ‘reflexive’ and ‘spontaneous’. They are less or perhaps differently amenable to anti-stigmatising interventions if at all. On the contrary, evolutionary factors involved in considerations such as whether to marry someone with mental illness are more amenable to conscious reflection
and decision making and so subject to different types of anti-stigmatising interventions. One can hardly imagine deploying cultural or political interventions to change the tendency of the mind to weight negative evaluations in preference to positive ones but these interventions are most suitable for mitigating deterministic interpretations of evolution which tacitly serve stigmatisers. Milk is necessary to induce the production of lactase but for this the genetic evolutionary machinery giving rise to lactase is not necessarily more ‘fundamental’ than the presence of milk in the environment. By the same token, social and cultural factors for example a ruthless, capitalist model of economy inducing and promoting unbridled pursuit of self-interest are not necessarily less fundamental than the genetic evolutionary machinery responding to such inducements.

We can use different terminologies and discourses and various fields of enquiry to delve into the same phenomenon. We can then endeavour to sum up the partial visions provided by each field into the synthesis of a picture which attempts to be the best possible approximation of reality. What one calls constitutional or economic or other origins are routes of enquiry into domains in which stigmatisation shows its face. They are windows onto the reality of stigmatisation. If one asked what was the origin of the production of energy in the body, dietetics refers mainly to food and calories, cellular biology primarily to mitochondria, biochemistry to the Krebs cycle and oxidative phosphorylation, physics to thermodynamics, etc. while all these are aspects of a single, ultimate mechanism: the fall of electrons to lower orbits around atoms releasing energy.

By the same token, all versions of the origin of stigmatisation, though divided and labelled by our mind as a distinct branch of knowledge, refer to a unitary, ultimate source: the pursuit of self-interest. We must not fall into the same trap that makes us stigmatisise, when trying to understand stigmatisation. The paradigms of physics, chemistry, sociology, politics, etc. have all human
dimensions, they all carry our traces, our tendency to divide, partition and parcel out, they are labels we have found to name the branches of what used to be called philosophy originally when we decided to cut it up into pieces. And we did so because of our mind’s lack of capacity to cope with the extent and volume of our accumulated knowledge and now none of these branches of knowledge on their own would give us a global picture of reality. We had to use reductionism and ‘create’ branches of knowledge and remain reductionistic even within most of the latter simply in order to understand, as this is what our constitution imposes on us. But we have the capacity to free ourselves from the same reductionism by recognising the limitations of our categorisations and by looking at the shared core of different versions of reality these branches of knowledge present: where these versions overlap is likely to be the nearest to where we can reach in grasping the essence of reality.

The theory of pursuit of self-interest is a general formulation that has the double advantages of tenability and coverage. It provides an account for several domains and in each domain it is able to cover the relevant evidence.
3.1 Sociolinguistics, Discourse and the Re-construction of Identity

3.1.1 Introduction

Though the term ‘sociolinguistics’ was coined in the 1950s (Romaine, 1994), sociolinguistics, as a discipline, was born at the 1964 Summer Linguistic Institute, a group of Protestant missionary linguists in the United States. This was preceded by earlier developments in sociology and anthropology which led to sociolinguistics. Sociolinguistics has been defined as "the study of linguistic behaviour as determined by social or cultural factors" (Longman Dictionary of English Language, 1984). In a wider sense it is also the study of how language reshapes thought and social behaviour and how discourse enacts relationships of power.

3.1.2 The Reflection View of Language

According to Herder (1803) language reflects the society that uses it and the experience and heritage of previous generations. This means that language, though partly reflecting the present social reality, also reflects traces of older, more traditional or past social realities. As Whorf (1956, p. 61) states “every language contains terms that have come to attain cosmic scope of reference, that crystallise in themselves the basic...thought of a people, a culture, a civilisation even of an era.” Though language may, to a certain extent, lag behind cultural developments, people intervene in language by changing grammar, inventing new vocabulary and styles to ‘help’
language come into line with the culture.

The reflection view proposes that language is a mirror of society and that social variations are reproduced in language. "Vocabulary is a sensitive index of a culture and changes of meaning, loss of old words, coining of new ones and borrowing of other words all represent the history of the culture itself" (Sapir, 1963, p. 27). Sapir considered linguistics as a social science and language as an aspect of culture. He proposed that language is a symbolic system for handling of all the meanings that a given culture is capable of and that new cultural experiences usually make it necessary to enlarge or modify the lexis of a language. This symbolisation of vocabulary is emphasised when Sapir states that "In a sense, the network of cultural patterns of a civilisation is indexed in the language which expresses that civilisation. It is an illusion to think that we can understand the significant outlines of a culture through sheer observation [of that culture] and without the guide of the linguistic symbolism which makes these outlines... intelligible to society." (Sapir, 1963, pp. 161-2).

Indeed, the vocabulary of a language can be conceptualised as carrying signs related to economy, politics, social issues, emotions, preoccupations, traditions, arts and climatic and physical environment of the speakers. Social phenomena such as the division of labour are also reflected in language (Durkheim, 1933). Languages extend their range and adapt to new patterns of interaction and new technologies (Ure, 1982). Scientific break-throughs, industrialisation, urbanisation and development of new service industries in modern societies introduce a range of new words and expressions into their language mirroring the above changes while the languages of isolated communities and secluded tribes remain free of such developments with a register (range of situation-specific varieties) reflecting a different socioeconomic and cultural
organisation. In modern societies, for instance, this phenomenon applies to a new range of vocabulary or meanings related to information technology (drive, diskette, software, microchip, hardware, Internet, hosting, modem, etc.). Vocabulary is not the only index of culture as, at least, some cultural elements are embodied in grammatical forms. An example is seen in languages using a large number of prefixes and suffixes having relatively concrete significance. The use in Kwakiutl and Nootka of suffixes defining activities as taking place on the beach, rocks or sea points to the nature of the physical environment and economic life of Indians speaking these languages (Sapir, 1912).

Based on the reflection view of language, one of the tasks of Sociolinguistics is to consider how social identities are expressed by language. For example, speech can reflect speakers’ belonging to a group Y as opposed to a group Z. The variety of words, expressions, accent and idioms used all refer to belonging to a certain generation, geographic area, social class, level of education and cultural background. For instance, when the use of non-standard third person singular simple present-tense verb forms without -s (e.g., he go) was studied in Detroit and Norwich it was found that only working-class speakers use these forms with any high frequency and this is more pronounced in Norwich than in Detroit. The smaller gap between the middle- and working-class norms in Detroit reflects the greater social mobility of American society (Trudgill, 1974; Wolfram, 1974). Also features such as pronouncing postvocalic /r/ before a consonant (e.g., in ‘the car key’ in England); glottal stops especially in a medial position (such as pronouncing ‘butter’ as ‘bu’er’ in most of Britain); omitting the /g/ in -ing forms (such as ‘singin’ for ‘singing’ in most of the English speaking world); and omitting /h/ in words beginning with it (such as pronouncing ‘heart’ like ‘art’ and ‘hand’ like ‘and’ in most of England) are used more frequently by speakers belonging to lower social classes. These forms are also more commonly used in some geographic
areas, e.g., pronouncing postvocalic /r/ in Scotland and pronouncing the initial /h/ in North England, Ireland, Scotland or America (Trudgill, 1974; Macaulay, 1977). The relationship between pronunciation and social class does not mean that every instance of a particular pronunciation identifies a person from lower social classes inasmuch as upper social classes too use these features but less frequently though sometimes practically not at all (for example, the use of glottal stops in medial position).

The reflection rules are more or less intuitively known to the general public and as Giles et al (1977, p. 322) mention "people are motivated to adjust their speech styles or accommodate, as a means of expressing values, attitudes and intentions towards others" (Giles’s theory of speech accommodation). In this regard, it is significant that when some of these pronunciations become stigmatised, the speakers might attempt to overcorrect themselves ending up using words that in fact do not exist. For example, some working class speakers in New York City generally pronounce words such as ‘Thirty Third Street’ as ‘Toity Toid Street’: as they realise that this way of pronouncing is stigmatised they revert all ‘oi’ in any word to ‘er’ in order to correct themselves when speaking to someone they consider as belonging to higher social classes, ending up referring to toilet by ‘terlet’ and boil as ‘berl’ which would stigmatise their speech even more than it was before.

In addition to social class, language can be marked by the speaker’s gender or age. Gender-related features include men’s tendency to interrupt women and to use rather imperative forms, women’s greater use of minimal responses to indicate support for the speaker, women asking more questions and their more frequent use of linguistic forms associated with politeness (Coates & Cameron, 1988). Societies which have loose definitions of gender roles show less differences
between gender languages (Wardaugh, 1986). By the same token, different age groups within the general population belong to slightly different speech communities (Labov, 1972). In Sweden young speakers aged 7 to 16 use a final t in verb forms more frequently than older speakers under the effect of the teaching of the standard written forms to the younger generation, the latter creating a differentiation of usages among different age cohorts (Romaine, 1994). Language can also be influenced by the speaker’s social network (Milroy & Milroy, 1992) in the sense that more widespread contact with the local community shifts the variety of language used towards that used by the community and this can even undercut the effect of the speaker’s social class on their language.

Languages can reflect social attitudes. For example, pronouns are subject to change in reaction to social and ideological developments. In Swedish the second person singular pronoun, du, has come to be more widely used across a broader social spectrum than previously. This is an indication of change in economic and political spheres in line with the egalitarian policies of the Social Democratic Party which by the 1990s had been in power for more than six decades in Sweden (Paulston, 1976). There has recently been an ideological move in the opposite direction with the election of a conservative government in the 1990s (Romaine, 1994) as yet to be reflected in language.

The reflection view of language is delimited. This is well expressed in what Lévi-Strauss (1963) said of language and culture: that there cannot be no relation at all and there cannot be 100% correlation. Labov (1972) states that some aspects of speech mirror some characteristics of social reality and other aspects of speech do not show any such correlation. Labov and Lévi-Strauss do not give any explanation as to why this should be so but it is likely that different social features
have different possibilities of penetrance in language and that different languages also allow
different degrees of penetrance of the social into their structure. In cases where languages allow
the social to infiltrate into them, "social pressures and attitudes....come to bear on linguistic
structure" (Labov, 1969). For example, there is in English an association between social class and
linguistic characteristics such as the use of the word ‘nothing’ in negative sentences. Lower
classes may wish to increase their status through copying the upper classes who serve to establish
the norm for the “rational individual striving for upward social mobility characteristic of the
philosophy of individual liberalism” (Williams, 1992, p. 72) even though, of course, the so-called
subcultures do create their own norm. Depending on sociopolitical climate and speakers’
motivations linguistic features are likely to be allowed to permeate differentially into the language
used by different groups. Speech variations then convey not only “information about the social
context” but also “the speakers' attitudes and intentions” (Gal, 1979, p. 12) i.e., personal
calculations of speakers in language use decisions (Breitborde, 1983).

As mentioned, different languages also allow different degrees of penetrance of the social into
their structure, for example, it is practically impossible to dismantle gender distinctions in French.
It is much easier to do so in English as in the latter comparatively very few nouns are gender-
marked (e.g., Steward, Stewardess → Flight attendant) and there are no gender-marked articles
(such as French le, la, un, or une) and pronouns which are gender marked (such as he or she) can
now be replaced by ‘they’. In French all nouns are lexicalised as either masculine or feminine,
each with their own specific articles, adjective ending (-e for most feminine adjectives) and ending
for past participles (-e for feminine past participles). One is then constrained by a medium which
conceives of universe as containing objects which are either masculine or feminine. Even if these
gender distinctions do not necessarily refer to concrete sex or gender differences, they emphasise
binary opposition, division and distance in the domain of ‘sex’ or ‘gender’. Conceiving of the universe as populated by ‘gendered’ entities, the French language thus resists efforts at making it a gender-neutral language much more than a language such as English does.

The reflection view of language is relevant for the study of how stigmatising attitudes are reflected in language. This will be demonstrated throughout the chapter.

### 3.1.3 Language Structure Shaping Worldview

Alongside the reflection theories there developed parallel views proposing that language delimits our thoughts. There were historical antecedents in ideas attributing a determining or delimiting function to language. Francis Bacon (Collected works, 1996) believed that though language was the means of communicating thoughts between humans, it limited reason and could lead to misunderstanding. Herder (1803) argued that language, in addition to reflecting history and society, is what conditions and delimits thought, and so it must influence other people’s opinion. Sapir and Whorf believed that language, e.g. the grammar of American Indian languages, influences the world view of the speakers (Whorf, 1956; Sapir, 1963).

The effect of language in determining our worldview, thoughts and behaviour was emphasised by Whorf, an insurance investigator who proposed that certain incidents were caused by the limits language imposed on our understanding. For example *This article is inflammable* is ambiguous and can be interpreted as ‘not flammable’ or ‘able to inflame’. Also, in Hanunoo, a Philippine language, our colours yellow, light brown and light green are all conceptualised by a single word:
malatuy; and red, orange and maroon, all by another word macara (Berlin & Kay, 1969) On hearing macara, e.g., the hearer would not necessarily perceive ‘red’. Instead, he or she may well perceive what the word ‘orange’ brings to the mind of an English speaker.

In demonstrating how the structure of a language can shape thoughts, Whorf showed that in Hopi, a North American Indian Language, there is no distinction between distance in time and distance in space. Also, verbs in Hopi do not give information about when an action happens, i.e. the tense, rather, they convey different types of information about the actuality and validity of the action. Verbs have validity-forms instead of our tenses. Reportive signifies a verb which conveys what has actuality, e.g., ‘He walked’; ‘She is speaking’; ‘We were eating’; ‘I see it’ but Hopi does not distinguish their tenses. Expective is a verb which conveys what is or was expected, for example, ‘They are going to come’; ‘She was going to run’; ‘It begins to rain’ again without the Hopi verbs distinguishing the tenses. Nomic is a verb which conveys information which is generally valid, for example, ‘She writes poetry’; ‘Certain dinosaurs laid eggs in sand’, as usual, the Hopi verbs do not distinguish the tenses (Whorf, 1956, pp. 113-115; 144-145). The structure of verbs in Hopi thus affects what is conceptualised, by the medium of linguistic forms, by the speaker and what is brought to the mind of the hearer.

Reality has to filter through conceptual networks of a particular language in order to be expressed and this reshapes it through that particular linguistic mould. Whorf (1956, pp. 213-214) proposed that “We dissect nature along lines laid down by our native languages. The categories and types that we isolate from the world of phenomena we do not find there because they stare every observer in the face; on the contrary the world is presented in a kaleidoscopic flux of impressions which has to be organised by our minds. We cut nature up, organise it into concepts, and ascribe
significance as we do, largely because we are parties to an argument to organise it in this way—an argument that holds throughout our speech community and is codified in the patterns of our language. The agreement is, of course, an implicit and unstated one, but its terms are absolutely obligatory; we cannot talk at all except by subscribing to the organisation and classification of data which the agreement decrees” [emphasis in the original]. The linguistic structure fashions ideas like a mould and what comes as product out of the linguistic mould is a version of reality, emphasised, attenuated, distorted or reshaped which attracts attention only to certain (modified) aspects of the original reality. Our perception of reality is thus influenced by the language structures representing it (though of course this does not have to be the only influence on perception). In the words of Sapir (1963, p. 162) “Human beings are very much at the mercy of the particular language which has become the medium of expression for their society... The fact of the matter is that the ‘real world’ is to a large extent unconsciously built up on the language habits of the group. No two languages are ever sufficiently similar to be considered as representing the same social reality. The worlds in which different societies live are different worlds, not the same worlds with different labels attached.”

Though objects are in general considered to be what they are called, there is some approximation in any language: “Language is at one and the same time helping us and retarding us in our exploration of experience” (Sapir, 1963, p. 11). Each word portrays a rough picture of what is intended and each phrase conveys an approximation of what is meant. A word is not an objective reality but a symbol channelled through our mind’s algorithms in order to take on a general meaning and serve as a coarse representation of a much more refined objective reality.

Sapir does not link his linguistic study specifically to stigmatisation. We use categorisation to
reach a gross understanding of people or objects and in doing so we lose sight of objects’ uniqueness and people’s personhood. Every word represents a generalisation, which, at the same time that it helps us have some overall grasp of the object in a quick and economic manner, sacrifices our understanding of the object’s distinctive character or action. If the word refers to people this may lead to stigmatisation. When the meaning is charged we are likely to stop there in the illusion of having grasped the truth, not bothering about further fine-tuning. A ‘schizophrenic’ means a ‘psychotic’, with all their commonly known negative attributions, and not someone with a different experience of the world, the enriching ordeal of withstanding a breakdown and possibly coming out of it, the experience of seclusion and isolation that other minorities have to face and an in-field understanding of what loneliness means for minorities.

In summary, the tenet that language shapes our worldview constitutes the essence of the Sapir-Whorf hypothesis though its stronger version proposes that language determines worldview. The hypothesis proposes that specific vocabulary and grammatical structure of a language shapes speakers’ and hearers’ thoughts. Chomsky believes that sentence structure reflects the universal structures of human cognition and that children are biologically predisposed to learn languages and that they possess innate templates for grammatical structures. Yet, Sapir-Whorf and Chomskyian hypotheses are not necessarily mutually exclusive as language can be a complex edifice acquired by the intermediary of innate linguistic templates yet specific grammatical structures of a given language can also limit the world view of speakers and hearers. In this perspective, grammatical structures of languages both depend for their acquisition on gross innate templates and reshape our worldview in its more specific applications. Nevertheless, the proponents of these views do not necessarily synthesize them in this manner.
One can hardly claim to have grasped all possible dimensions of an object as one is always likely to be limited by one’s own point of view or angle of thought. ‘Objectivity’ is likely to involve varying proportions of subjectivity which means that the same object could be represented in various forms all professing to be a true representation of reality. As such every language, even though constraining and limiting our worldview by its structure, can still construct different ‘realities’ out of a single object by the way the language is deployed. The manner someone uses a language, consciously or unconsciously, influences what is perceived as real and can make others see things their way. In other words particular uses of any language place further checks on reality and can mystify agency, causality and responsibility.

The structure of sentences can influence our perception of, for example, agency. In an example Sapir demonstrates how we never really get beyond what is suggested by the forms of our speech. “‘The grass waves in the wind’ is shown by its linguistic form to be a member of the same relational class of experiences as ‘the man works in the house’ ” (Sapir, 1963, pp. 10-11). To clarify for ourselves the notion of agency we need to move to another cognitive level and argue ‘the grass is waved by the wind’. We start to know more about a phrase from the moment we start to ask ourselves a question about it. The second and further questions would fine-tune our understanding of the concept and take us one step further towards the truth. Understanding is an exercise of being “the most relativist...the least taken by the form of [our own]...speech” (Sapir, 1963, p. 165) but we will never reach absolute truth as there is no limit to further understanding.
The idea of how particular uses of language place particular constraints on reality is the essence of Orwellian thought control (Orwell, 1946). In nondemocratic regimes language can be used to distort or hide objective facts in a cloud of rhetoric yet this is by no means limited to these regimes and can also be found in Western democracies. An example is the Pentagon’s referring to a deadly missile as ‘Peacekeeper’ even when it is actually used in a war. A piece of news such as ‘Twenty were shot today in clashes between demonstrators and police in Peking’ can be a dampened-down version of a more shocking item of news: ‘police killed twenty demonstrators today in Peking’. The first version implies that some of those shot might still be alive and that some of those shot might even be police officers shot by armed demonstrators. It also implies that this is something ‘done’ passively rather than something someone ‘did’ actively or deliberately. As such, the passive voice flattens the trenchant expression of agency, probably dampening the emotional impact of the news at the same time.

Power is exercised not always through coercion or force but through rather abstract entities such as discourse, i.e., social practice. With discourse language exerts social control (Boulet, 1985; Bolinger, 1980) and sociolinguistics, in a wider sense, is the study of how particular uses of language as social practice or discourse maintain social roles (Foucault, 1972) although the analysis of discourse is not traditionally part of Sociolinguistics proper.

An example of discourse related to schizophrenia is the following. To say “he is a person who has an experience of schizophrenia” instead of “he is a schizophrenic” would imply all the need to respect the individual by referring to him as a person; positive, experiential rather than corruptive nature of the process (suggested by the word ‘experience’ versus the ‘infective’ connotation of the suffix ‘-ic’) and a general implication of the necessity to act fairly towards such
a person (by using a more cumbersome expression ‘to make a point’ in reference to the status quo). The discourse “he is a schizophrenic” does not denote any of these ideas and can be shown metalinguistically to imply (and so enact) objectification, distancing and stigmatisation. (see below).

The illocutionary impact of the mere utterance of certain words help understand how discourse can ‘perform an act’ and why discourse is indeed a variety of ‘social action’. There is a feeling, particularly among ‘primitive’ peoples, of close identification between a word and the thing it represents which underlies the magic of spells (Sapir, 1933). As Boulet (1985) indicates "the words, the discourses, are not simply the representation of our acts and of our thoughts. They are not only there to transmit information, ideas or orders. They are not just the reflection of the social, they are a participating force and are active on the social and produce specific effects.” (emphasis in the original) (translated in Williams, 1992, p. 256).

This implies that language is not just a mosaic of words and phrases but a dynamic structure, constituted of discourse, social practice and social action, enacting relationships of power. Discourse is ideologically-based and ideology is in the service of power. On one hand, by the use of certain words and gestures the elite elicits work, taxes, blood and applause from the masses (Laswell, 1936), on the other hand, the counter-elites create whatever linguistic symbols supposed capable of functioning as a strong message to develop social consciousness and political struggle. This is how language acts as discourse in national movements for independence such as those of Jews, Algerians, Bengalis and the Irish (Cooper, 1989). Discourse can be used by the dominant class to maintain and reconstruct class or ethnic boundaries (for example, when a policeman in the Southern US addresses a black physician as ‘Boy’) or by the oppressed and the stigmatised...
to challenge the existing social order (for example when a patient challenges other people’s use
of the term ‘schizophrenic’ to refer to him or her). Employing language as discourse in order to
maintain, reinforce, reconstruct or contradict other social discourses such as ageism, racism or
stigmatisation of patients is indeed part of the social — not just representative of social — it is
part of society and then itself social.

Chomsky, despite being committed to political activism was quick to show his surprise when
asked to speak on Language and Freedom. He found the proposed title of the lecture puzzling.
“In what way”, he wondered, “are language and freedom to be interconnected?” (Romaine, 1994).
The variety of the study of language Chomsky proposes resembles cutting off and studying the
mathematical formulae out of textbooks of Physics, ignoring all their connections to the
environment and, at the same time, not acknowledging that they have any practical application
at all. Language is discourse and discourse is larger and more complex than the meaning of a
single word or the sum of individual words or syntactic rules governing sentences. Discourse is
the practice of social and/or political and moral order and like every other social act “reproduces
or subverts a social institution” (Pateman, 1980, pp. 15-16).

The use of the title boy to refer to adult black men is offensive as can be seen in Dr Poussaint’s
account of being stopped by a white policeman in a southern town in the United States (Ervin-
Tripp, 1972). In the following exchange the policeman puts Dr Poussaint in a subordinate position
by refusing to address him by his proper title:

‘What’s your name boy?’
‘Dr Poussaint. I am a physician.’
'What’s your first name, boy?'

'Alvin.'

In the above exchange, the word ‘boy’ potentially mystifies the identity of the physician, at least for a moment, for those present who may have partial knowledge of the black man or who are unsure what attitude one should or could adopt towards the black in the first place. The attribution ‘boy’ creates some adulterated identity for the physician and acts as a variety of discourse for social control. This discourse reflects the policeman’s psychological and political stance, but also the institutional and social stance of racism. His discourse is likely to reinforce racism, by proposing, at least in the context in which the exchange happens, an infantilised version of the identity of the physician: a ‘boy’. Though he is not a ‘boy’, the proposition that he is, potentially mystifies his integrity and adulthood in the minds of those who have some half-avowed attitudes similar to or shiftable in the direction of the one openly declared by the policeman. The practice of the policeman is to write down a clause in the registry of the physician’s identity or at least an attempt to do so. The physician’s sense of his own identity may be firm in the sense that, in the above circumstances, he may not be belittled by means of his possible psychological strength yet, by the mere use of language, the boundaries of his social identity are shown to him and others present, to be subjectable to attempts at manipulation, intrusion and re-negotiation, and this vulnerability remains at least as an addendum to his social identity. The physician still remains a physician yet with the additional feature that he is a physician whose adulthood and dignity someone denies by calling him ‘boy’. In this example, language reflects and affirms the existence of a particular social relationship between the speaker and the addressee, defines and reshapes that relationship and attempts to reconstruct a new identity for the physician. This is not just an extreme example. A simple request for opening a door (Montgomery, 1995) can be couched in
several different ways each reflecting, shaping, reconstructing and enacting a somewhat different social relationship between the speaker and the addressee as the following examples shows:

1. ‘Hey!’ (*Meaning ‘Open the door!’*).

2. ‘The door!’.

3. ‘I want you to open the door.’

4. ‘Open the door, James.’

5. ‘Do be an angel and open the door.’

6. ‘Please open the door.’

7. ‘Is the door still closed?’

8. ‘Could you possibly open the door.’

9. ‘You couldn’t by any chance open the door for me, could you?’

10. ‘I wonder if I may ask you to open the door, Sir!’

Language which attempts to write down a clause in the registry of a person’s identity does not
need to be made of words. It can be non-verbal, e.g., acts of aggression or subtler forms of behaviour such as walking away, standing apart or throwing a glance connoting similar propositions about the person’s identity. Though the virtual identity of a person based on who they are may remain as it is, what is expressed verbally or non-verbally about a person can act as a proposition which, even if wrong, will act at least for some time as a smear on their virtual identity.

The idea that particular uses of language can construct a social reality through influencing thought processes has some experimental support. The way any idea is presented is likely to affect the mental image conjured in the minds of the addressees. The feminist literature refers to experiments that have established that women feel excluded when they read texts with masculine generic he. In further experiments when people (men and women) were asked to make drawings to go with the texts, they tended to draw men (Romaine, 1994). Later on, women who reformed their linguistic practice by using non-sexist generic pronouns tended to draw more women figures when given similar texts. It is possible that a third factor such as feminist campaigns influenced women’s thought processes leading them to revise both their linguistic practice and tendency to draw more male figures yet even those feminist campaigns worked by the medium of discourse.

In summary, language is used as discourse in interpersonal, social or political agendas and contexts, and as such can reflect, reshape or reconstitute social order, identities and roles. Language mirrors society, fashions ideas, reconstitutes identities and enacts political causes. For example, patients’ request as a group to be referred to as ‘schizophrenia-sufferers’ rather than ‘schizophrenics’ reflects the social reality of patients’ solidarity, reshapes the idea of their being sufferers, engages interlocutors in a discourse of value and makes an attempt to reconstitute a new
3.1.5 Classification and Stigmatisation

There is a classificatory suggestion in linguistic terms. The roots of human language are likely to lie in the capacity of the higher apes to solve specific problems by abstracting general forms or schemata from different situations which led in early man to an ability to develop linguistic symbolism (Sapir, 1933). The Kantian theory stipulating that the mind filters sensations through categories in order to perceive them is relevant here as the mind seems to process words in the same manner. Words typify and categorise. They are an index of what humans have classified in order to make sense of the world. This means that any language is indeed a system of classification.

Though every language is a system of classification, there are other systems of classification embedded within a given language. Items which are classified as similar in one cultural setting may not be seen as such in another. Foucault (1972) repeats Bourges’ ‘ancient Chinese encyclopaedia’ which divided animals into the following categories: 1) those that belong to the emperor, 2) embalmed ones, 3) those that are tamed, 4) suckling pig, 5) mermaids, 6) fabulous ones, 7) stray dogs, 8) those included in this classification, 9) those trembling as if they are mad, 10) innumerable ones, 11) those drawn with a very fine camelhair brush, 12) others, 13) those that have just broken a water jug, 14) those that look like flies from a distance. This sort of classification tells us a great deal about the fictional setting in which it developed. It also indicates similarities as its basis but similarities which are each in a rather different domain and not
subjected to overriding or systematic criteria.

Similarities are not the only basis for classification in different societies and associations can play an important role. In Dyirbal, a language spoken in North Queensland, nouns are preceded by a classifier indicating the category to which they belong. The *Balan* class includes women, birds, dogs, dangerous things, fire, water, sun or stars. The *Bayi* class includes men, snakes, bats, kangaroos and most other animals. The *Balam* class includes all edible fruits and the plants that bear them, and the *Bala* class includes body parts, most trees, bees, mud and stones. Birds are not in the second category with men and most other animals, as to the Dyirbal, birds are the spirit of dead women (Lakoff, 1987). Fishing equipment, lines, hooks, etc., because they are associated with fish, are categorised with the fish in the Bayi class. It is interesting to notice the stigmatising grouping of women, fire and dangerous things into one category. This ‘association’ represents the local cultural beliefs about women. Romaine (1994, p. 114) reports that one male speaker associated fire and danger to women in saying...buni [fire] is a lady... It’s a lady. Woman is a destroyer. ‘e destroys anything. A woman is a fire.”

We have a tendency to classify, categorise and systematise information in all phases of our memory processes. One of the aims of classifications is condensation of information and building of general concepts which can help gross understanding and memorisation. When objects are classified on the basis of at least one common denominator generalisations become possible. Knowing that an item belongs in a given group one already knows a certain number of characteristics of that item. For example, if people are asked to recall animals and given few minutes to do so, they recall animals in groups of related creatures, e.g., birds, cattle, sea mammals etc., recalling some members of each category before moving on to another category.
Classifications help us with our cognitive tasks, yet, they constitute an oversimplification of the external reality in that a spectrum of items are represented by just some common denominator. This oversimplification is the price we pay as our mind, attempting to cope with the influx of data, categorises objects and events and as such economises on resources of memory and perception (Macrae et al, 1994a). As mentioned earlier, the simplification involved in the process of stereotyping free up cognitive resources for use in other tasks, and functions as a labour-saving device which provides us with quick-and-easy stereotypes at the expense of sophistication and depth. The resulting imprecision and gross generalisation is one of the cores of stigmatisation.

One variety of classification is that of diseases and in relation to the subject matter under study classification of psychiatric disorders. Psychiatric classifications are maintained by the power of psychiatric experts. The essence of these classifications is reconstituted and reproduced by educating doctors and is supported by a paraphernalia of medical dictionaries, glossaries and codification systems which have infiltrated the language of insurance, courts, social research and science laboratories and some of them, like DSM-IV™ (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; American Psychiatric Association, 1994), have been even registered as a trade mark. Classifications provide psychiatrists with a device they can use to allocate formal diagnostic designations to people in order to commit them compulsorily to psychiatric hospitals, to influence court judgments affecting freedom of individuals and to define
populations subjected to their care. Even a mild to moderate recurrence of an illness such as schizophrenia can be used, with the powerful implications of the word, to justify admitting the patient legally to hospital “for the sake of the patient’s health or safety” which could lead to stigmatisation. All medicalisation introducing a new category in psychiatric classifications increases the power of psychiatrists by extending their contacts, audience, scope of activity and range of involvement in medical, social, legal and political spheres and their possible involvement in stigmatisation.

Classifications can contribute to stigmatisation in several ways. Though categorisation can be considered as a manifestation of human concern in confronting enormous masses of disparate pieces of knowledge, findings and experiences and it does reduce patients’ and clinicians’ anxieties in relation to their uncertainty as to the diagnosis, treatment and prognosis, it can also create new anxieties when the diagnosis is stigmatising, the treatment difficult and the prognosis poor.

While attaching a name to a condition may create an impression of understanding it is, at the same time, likely to lead to rejection and distancing. It has been historically very comforting for doctors to conceal their ignorance from patients by clothing it in Greek neologisms (Kendell & Zealley, 1993), yet these Greek neologisms and similar important-sounding terms could be easily loaded with stigmatisation. The language of medical practice is conveyed to the general public via the mass media and can objectify stigmatisation. Giving a diagnosis such as ‘schizophrenia’ seems to serve save doctors’ face before a lay public who regard psychiatrists as omniscient. Yet, the name of an illness does not necessarily describe a person’s capabilities. An illness can occur with varying degrees of severity and those affected may have particular existential values and technical or artistic talents independent of their illness and the assessment of these strengths and talents is
likely to be beyond the remits of psychiatrists. Categorisations produce this misconception that all persons described as e.g. schizophrenic are alike in all important ways. While other aspects of their individuality and uniqueness are pushed into a defocused background, the disease is portrayed in the foreground as a convenient sum-up for society and ‘for the person’ themselves. As such using such designations make patients nameless, faceless and personless.

As the international psychiatric taxonomies are mainly Western cultural efforts to understand illness, they are loaded with Western values for example in their definition of ‘illness’: a condition is defined as illness when it is considered sufficiently impairing. So, while in Algerian (Al-Issa, 1989) and Latin American cultures (Reiss, 1986) premature ejaculation is viewed positively and is not considered as impairing it is classified as a Sexual Dysfunction in ICD-10 (International Classification of Diseases, version 10, WHO, 1992). Certain non-Western cultures may have higher tolerance for certain symptoms (e.g., dependency traits or states) and much lower tolerance of some other conditions (e.g., substance misuse) (Doi, 1974). The literature on the Japanese concept of *amae* (sweet dependence) (Wierzbicka, 1991) indicates that the word *amae* is central to the emotional atmosphere of the Japanese culture. Japanese psychiatric patients would commonly say to their doctors: “I am completely in your hands” and, in this context, experience kinship with and express their dependent position as a ‘child’ vis-a-vis nurses and doctors who approve of and even nurture that dependent position (Caudill & Doi, 1963, Yamamota, 1972, Nomura, 1987a,b). Similar expressions of dependency in a Western psychiatric setting even by a Japanese patient may be considered pathological and the diagnosis of Dependent Personality Disorder invoked from the psychiatric classifications, stigmatising a person who is behaving in a way congruent with their own culture. In the Caribbean, schizophrenia is not designated as such and is considered as a supernatural phenomenon brought about by spirits though usually by the
persons’s own agency (Littlewood, 1988). An African-Caribbean family in the West may feel confused and stigmatised and be unwilling to agree with a doctor who, using the Western classification systems, tells them that their relative has an illness called ‘schizophrenic’ resulting in lack of cooperation with and distrust in psychiatric facilities (Kiev, 1961), prolongation of illness and consequent poorer prognosis.

Psychiatric classifications suffer from an additional epistemological problem in that many of their categories are based on symptoms rather than on biological markers. As such, a range of possibly etiologically different conditions with similar symptomatology and different prognoses could be grouped under a single category, e.g., schizophrenia and stigmatised en masse. Also, psychiatric classifications by the fact that they are mainly symptom-based could promote a mechanistic approach to assessing patients, leading to the feeling in patients that they are being handled as a ‘set of symptoms’ reinforcing possible feelings of objectification and stigmatisation. Further, the existence of psychiatric classifications may imply the necessity of finding a name for problems of everyone who would consult a psychiatrist, as such leading to reification, concretisation and stigmatisation. For example, people whose psychological structure exert adverse effects on their relationships and who require psychotherapeutic attention may not constitute a personality aberration so severe as to be described as a ‘disorder’ (Chodoff, 1987). Having parts to one’s personality which functions less well than other well-functioning parts would not necessarily make the whole person ‘an ill individual’, yet people are sometimes regrouped unscrupulously under the sweeping category of Personality Disorder. This process is facilitated by the existence of systems of classification.

Classifications may also deny or explain away political and social problems by pigeonholing ‘those
who protest’ as “ill” or “suffering from personality disorder” or in short “PD”, as such representing their struggle as a sign of some dysfunction. Whether the individual suffers from some degree of illness or not, all instances of their political activity and possibly constructive criticism of bureaucratic, administrative and political discourse, however open-minded and just, can conveniently be explained away as some other manifestations of the alleged illness. Similarly, a person’s awareness of an out-group gossiping about or stigmatising his or her ‘deviant’ discourse can be misinterpreted by the medical establishment as a “persecutory feature” or evidence of “psychosis” or “paranoia.” The attribution of such labels can elicit offended, frustrated or enraged reactions from the person, making the diagnosis a self-confirming hypothesis. Behaviours, opinions and reactions of the person are then considered to have all only symptomatic value for confirmation of the ‘diagnosis’ already allocated (Egeland et al, 1983). One can observe that even if we suppose that the person suffers from a psychiatric condition, the attribution of the diagnosis can be inevitably exploited to downgrade the political aspect of their stance and stigmatise them.

Human beings are active in defining the world through the categorisation of people into groups. Social boundaries are maintained through evaluation of relative power, health, material possessions and other social attributes. A distinct status is commonly denoted by a categorical noun. Though psychiatric classification are primarily used for making diagnoses and recommending treatments (already what only someone in a position of power could do) they also contain a discourse of value enacting subject positions by allocating loci along implied scales: doctor, patient; healthy, ill; sane, insane, etc. Classifications can then lead to stigmatisation when looked at with parallel thought. Inasmuch as they are inherently based on distribution of value and attribution to a hierarchy they entail treating people either as “non-persons” (e.g., ‘schizophrenics’), highly respected persons (doctors including those who compiled the
classifications) and those not even worth mentioning: neither doctor nor ill!

Classifications vary in the extent to which they lead to stigmatisation. DSM-IV requires a duration of illness of at least six months for the diagnosis of schizophrenia to be made while the duration required by ICD-10 is only four weeks. In this context, using DSM-IV criteria fewer individuals would be diagnosed as having schizophrenia. Even if the longer duration suggested in DSM-IV is there mainly to make sure that a continuous mental abnormality has been present over a period long enough to warrant the diagnosis rather than for the sake of avoiding stigmatisation, these stricter criteria would prevent making a potentially stigmatising diagnosis for those who may not require or deserve it. Nevertheless, those diagnosed with schizophrenia using DSM-IV criteria tend to be selectively patients with a more chronic illness of poorer prognosis and this may in turn increase the stigmatisation of whatever is presented as ‘schizophrenia’.

One can argue that categorisation would act as a message to the patient that there is a problem with his or her health, acting as a symbol soliciting insight into their own condition. While the acceptance of a diagnosis by the patient might be a necessary pre-requisite for adherence to the treatment, there is no evidence to suggest that, for this purpose, the diagnosis has to be the most stigmatising. Also, it does not follow that there is a need to speak about the diagnosis or draw undue attention to it most of the time as this would not help the individual find some space to negotiate a new identity outside that of a ‘psychiatric’ or an ‘ex-mental’ patient.

Some authors have questioned the epistemological value of classifications in psychiatry at least as far as neurotic disorders are concerned. The controversy over the value of psychiatric classifications has further intensified as, in many epidemiological studies, the incidence of co-
morbidity of psychiatric disorders is higher than the co-morbidity of physical disorders in other branches of medicine (Pichot, 1994). The latter raises doubts about the validity and real boundaries between psychiatric categories. Kleinman (1988, p. 59) attempts to argue “even when genetic predisposition and neurobiological vulnerability convert the experiential effect of social pressures, here into panic disorder, there into depressive disorder, the socioeconomic transduction, can be with greater parsimony configured as simply social distress. Seen from this wider perspective, what is important is not so much the diverging forms of the psychobiological response as the similar social antecedents.” If, for neurotic disorders, treatment specificity is not as clear cut as originally claimed and there is also little evidence that their causes are distinctive, can we conclude that one does not need any classificatory system in psychiatry? What about dementia, Huntington's chorea or alcoholic hallucinosis?

Having considered the stigmatising features of classifications, one should also recognise aspects of classifications which temper stigmatisation. The medical model emphasises vulnerability (Jellinek, 1960) and human innocence. Inclusion of an entity in psychiatric classifications would imply sickness rather than wickedness of people suffering from that condition. There has been a great decline in the stigmatisation attached to alcoholism (Gaines, 1985) since it was defined as a disease as this exonerates those affected, to some extent, from responsibility for having developed the illness. Another aspect of the medical model is that it may be used as a way of redistributing income and dealing with the problems of poverty and unemployment (Stone, 1984) [partly caused by stigmatisation] through disability claims for low grade chronic problems which can enter listings of social security offices (Kopleman, 1984; Kleinman, 1988) following their official recognition in psychiatric classifications.
Classifications are essential for diagnosis, prediction of outcome, appropriate treatment and care for patients: interventions which are likely to reduce stigmatisation. Classifications allow compiling and analysing scientific data which would help discover a better treatment or cure for the condition leading as such to attenuation of stigmatisation in the long run. Also research into a category may provide scientific evidence of 1) a biological causation implying at least some degree of blamelessness (as mentioned in the case of alcoholism) or 2) a lack of cause and effect relationship between that category and a negative attribute. For example, the finding that a certain category, e.g., epilepsy is not associated with criminality is likely to lead to a re-evaluation of people afflicted with the illness and a shift in the corresponding social attitudes.

Classification facilitates teaching. It provides a common language for educational purposes and encourages students of psychiatry to pay attention to specific patterns of mood and behaviour with consequent recovery for patients and reducing stigmatisation. The idea of developing a common psychiatric language among nations through standardising categories and drawing up operational criteria is, in itself, an indication of sensitivity to better intercultural communication and more systematic treatment and recovery of patients worldwide which reduces stigmatisation.

Classifications may ‘benefit’ society for example when a person with ‘uncontrollable epilepsy’ is not allowed to fly an aircraft or to drive a bus. This would also benefit the individual concerned as he or she would be spared from probable danger though he would still be exposed to whatever stigmatisation is attached to epilepsy. The ‘labelling’ resulting from the classification systems would also benefit the person when it draws other people’s attention to his or her need for help, social, psychological intervention and remedial action. A minority of patients in my survey actually preferred the designation ‘schizophrenic’ for themselves as they believed this would bring
them more social, psychological and medical help (see chapter on results).

In summary, classifications have both stigmatising and anti-stigmatising features. Though they can be handy tools in the service of stigmatisers, classifications are necessary devices for scientific research and development of cure for stigmatised conditions. From a more inclusive perspective there are enough good reasons for them to be maintained and supported with reservations about when they are employed as discourse in the service of power and stigmatisation.

3.1.6 Language and Identity

One can argue that language is connected with identity in that it expresses and contributes to people's sense of who they are. For example, the discourse of Alcoholic Anonymous (AA) consists of requesting its attenders to own and acknowledge alcoholism as a pivotal element of their identity. At AA meetings the speaker stands up and introduces himself or herself first as an alcoholic and then by their first name: "I am an alcoholic. I am James." This shows how designations such as alcoholic can be introjected or, at least, appropriated and become part of identity of a person just as a first name does. Though the emphasis on alcoholism is placed in order to declare awareness and ownership, in other circumstances people may decide to live their designations: I'm a criminal so I'd better rob someone. I'm a schizophrenic so let me behave madly whether I am mad or not. I'm an alcoholic so I'm supposed to drink heavily.

Interactions between those recognised as bearing a stigma and other people crystallise in society's linguistic formulations of stigmatisation. These are varieties of discourse and stigmatisation is
carried in part by these linguistic formulations. Changes in a categorical designation can alter understanding (Bolinger, 1980) and as each form may convey a different evaluative and emotional connotation it is likely to determine what concepts are retrieved by the hearers and thus the immediate societal response.

Lexicons referring to schizophrenia in different societies are likely to reflect particular conceptions of the illness and act as discourse to reconstitute the identity of patients. These lexicons are likely to influence the course of the disease through the expectations they arise. The Yoruba word generally used in Nigeria (a country with a comparatively good prognosis for schizophrenia) by family and doctors to refer to a patient with mental illness is alaisan or arao (person with illness) rather than oridaru or were (mad person) (personal communication by a number patients, relatives and citizens from Nigeria). The patient is usually considered a victim (Prince, 1964) of some external malevolent agency. Only rarely do Yoruba families consider the patient as the agent bringing about his or her illness by personal decisions or actions. The response of the relatives is generally to provide support, care and sympathy towards the afflicted person, especially when they have only mild or moderate symptoms (Prince, 1964) and to remove them to another area to get help from doctors or lay healers there, thus protecting the patient from any adverse social response in their immediate environment. This suggests that there is actually some harsher discourse in society at large yet the highly tolerant discourse of the relatives and other close persons would come to mitigate it.

Lay people in Columbia, like Mexican Americans (Jenkins, 1988a, 1988b) similarly rely on conceptualisations such as nervios (nerves) which minimise (if not actually obviate) stigmatising attributions by calling the relative with schizophrenia as one having nervios. This discourse
reflects aspects of the local culture in which strong family bonds and solidarity foster tolerant inclusion within the home of the family member having nervios yet it again suggests the existence of a harsher discourse in the wider society that the ‘nervios’ discourse is constructed to oppose.

Southern Asian societies use certain traditional narrative schemata to deal with the stigmatisation of chronic illness or disability. Thus the historical figure, Surdas, was blind; he became a saint after having written his poems to a deity; this is constantly used as a moderating factor against the stigmatisation of blindness; anyone who is blind is called in Hindi eponymously ik surdas (and not ik andha: a blind person) (personal communication from Dr Basu, Cultural attaché, High Commissioner for India in London). Mental and physical illness are not universally allocated to distinct categories: epidemiological studies which have examined the impact of stigmatisation among Indian patients with psychotic illness (Malhorta et al, 1981) have ignored those patients who attend religious healers, and who thus avoid the Westernised psychiatric services in India and remain relatively unmarked in the cultural and religious context of their own community (MacDonald, 1981; Skultans, 1987). These people would not receive any diagnosis. ‘Absence of lexicon’ is a variety of ‘linguistic intervention’ in which the illness is not objectified and so not allowed to adulterate the identity of the person. In the WHO Determinants of Outcome Study (Sartorius et al, 1986; Jablensky et al, 1992), 73% of the sample in Agra had only seen traditional or religious practitioners before being located. It appears likely that religious or traditional healers seldom send a patient back into the community with a diagnosis of sanki (schizophrenic), contrary to Western clinical practice which privileges biomedical categorisation over social context (Littlewood, 1990).

The linguistic effect of the word schizophrenia itself in the West, implying medicalisation and
representing a greater reality than madness or lunacy should be emphasised. All the same, patients and relatives are now likely to reject the word in general and consider it to be pejorative even though a minority of patients are likely to internalise the social stigmatisation and consider themselves as schizophrenic or use the word for compensatory purposes. The nominalised categorisation of psychiatric patients has recently been recognised as stigmatising and is avoided: mental health charities have recently promoted 'learning difficulty' and 'mental handicap' which cannot be easily employed as evaluative nouns that allocate individuals to a lesser status (cf. 'retard', 'idiot'). DSM IV states that it will not use such expressions as 'a schizophrenic', but rather 'an individual with schizophrenia'. Yet, in two major reference texts for psychiatrists in Britain (Gelder et al, 1990; Kendell & Zealley, 1993), the noun 'schizophrenic' is frequently employed.

We may argue that an individual first achieves a social identity through their name, designation or title. Names function as the “most important symbol to provide anchorage for self-identity throughout the life” (Allport, 1937, p. 127). To reply to Shakespeare’s question of ‘what’s in a name’, we could say : a person’s social place (Romaine, 1994). Titles and other forms of address are sensitive indicators and builders of status and their pivotal function in the West is commensurate with the central position assigned to the individual in Western culture. Althusser (1995) argues that society interpellate us as persons it wants us to be and this contributes to the construction of our identity: if someone in a public or private place calls out “Hey, You!” and you turn around you have considered yourself as the one being identified and hailed (Romaine, 1994).

Some sociological interpretations stress the way individuals make their identity through or against interpellations and ascriptions of names or designations (Estroff, 1982; Langness & Levine, 1986); others place particular emphasis on the social process of labelling in itself (Scheff, 1974). It is
likely that the effect of ascription of labels on identity of the addressees is partly mitigated by the
degree of their inner resilience, security and emotional stability yet this should not be taken to
exonerate stigmatisers as identity is likely to be, at least in part, constructed from outside.

A change of name or title by a woman on getting married, by an officer promoted in an army, by
a monk on entering a monastery, by a university teacher in taking up a new academic position,
or by a pope on assuming office is indicative of the adoption of a new role and a break with the
older ones (Bering, 1992). Designations declare to society and resonate to ourselves who we are
or the sort of person we are proposing to be or being pressured to be by others (Drury et al,
1980). Based on our title, others react to us by what that title suggests to be our social value,
identity or attitudes. These reactions are likely to affect our ‘self’ and reinforce or weaken our
self-esteem and, in a sense, reconstitute our identity.

Names can be consciously exploited as weapons for stigmatisation in conflicts between ethnic
groups (Morgan et al, 1979) forcing the stigmatised to adopt alternative, more prestigious names.
A decade before the start of the Second World War some people of Jewish background in
Germany were, as a means of stigmatisation, given nicknames related somehow to their names
sounding differently from German names. When a minority struggles to be accepted by a majority,
they hide or re-present their unwanted or stigmatised identity for example by changing their names
or alternatively form a subculture. So there was a move among these people of Jewish background
towards the first option, i.e., to change their names. These name-escapes indicated a wish to
avoid social stigmatisation which, years later, showed itself in the Holocaust. The move for name
changes was intense and, like a barometer, showed the pressure under which Jewish people were
struggling (Broom et al, 1955) although the same Jewish names, in another context such as in
modern Israel, could function as a means of increasing cohesion and promoting the feeling of being members of a special group or culture.

Barriers were raised to block the changes of Jewish names into Germanic names and almost all changes of Jewish names allowed between 1933 and 1938 were changes from Jewish names to only other Jewish names. In 1938 a law was promulgated on the compulsory changing back of every change of Jewish name prior to 1933, if the change was considered ‘undesirable’, no matter when it was granted, no matter whether the person involved was still alive or had already died. All compulsory reversals had to be completed by the end of 1940 and therefore were declared ‘urgent matters’. While revocations were being carried out, a decree was published that names Israel and Sara were to be compulsorily imposed on every ‘Jew’ without a markedly Jewish first name, indeed in order to mark them. The Ministry of Interior, to guarantee recognisability once and for all, compiled a list which specified those first names which were to be the only ones permitted for Jewish people in future. These were tactics to identify Jews by their names, a step to the order of 15 September 1941 which made the marking visible. Every Jew had to wear a yellow star on their clothing. This visual stigma was later on replaced by numbers burnt into their skin — a concretisation of the linguistic stigma back into the original meaning of the term: a mark put on slaves making them unmistakable objects. In some cases the defectiveness of the Gestapo linguistic competence as to determining the Jewish derivation of a name could rescue lives. Linguistics was a matter of life or death. Though name changes by Jewish people reflected their wish to escape from bullying and political persecution, a considerable number of change of names had started much earlier and it is likely that the adoption of more ‘integrated’ Germanic names infused Jewish people with feelings of self-esteem due to assimilation into a higher-status category and helped with the redefinition and reconstruction of their identity.
Society can force people into adopting certain identity positions by the way it sanctions those who adopt alternative positions. When people are pushed into adopting a particular identity, by the force of repetition of the adoption, they are likely to end up at last taking on that identity. In the early 70s in the US the term black as compared with Negro suggested to many white Americans a more critical and less conforming attitude towards the dominant society because of its association with minority protest. This was corroborated by an experiment (Katz et al, 1975) in which black people who asked for help by requesting white people to take part in a brief consumer-survey interview and who presented themselves as ‘Negro’ rather than ‘black’ had more chance of getting assistance. To get help black people had to introduce themselves as Negro which can act, on its own account, to reinforce and reconstitute a ‘Negro’ identity.

What we are called (or accept to be called) is likely to have important implications for how we feel about ourselves (Drury et al, 1980) and so for our personal identity. An evaluative investigation by Drury et al looked at 98 American students who were studying at the University of Copenhagen for a year. Those students who had translated their name into Danish had come into a deeper contact with the culture of the host society. Precise measurements of the self-esteem of the students was carried out using Rosenberg’s ten-item index on their arrival in Denmark and on their return to the States. Though self-esteem upon arrival was inversely related to the likelihood of forename alteration, the relationship was not statistically significant. Seventy five per cent of those whose self-esteem increased during their stay in Denmark were those who had adopted a more ‘integrated’ name while less than forty per cent of those whose self-esteem had declined had adopted such names, the difference being statistically significant.

One can reflect on how the structure of English can shape the thoughts of its native speakers as
the Sapir-Whorf hypothesis predicts. And what about stigmatisation in particular? Reviewing the literature, one finds that English is a nominalised language of which what its speakers are most consciously aware are the substantives. English speakers first think in terms of nouns — verbs are there to link nouns and noun phrases (Phoenix & Lindeman, 1982). People are frequently called by substantives based on the name of their illness, e.g., a schizophrenic even by medical professionals. As one of the patients in my survey stated “Diagnosis is already a name.” People are not necessarily what they ‘are’ but what they ‘become’ by being inserted and constrained into subject positions created by systems of classification. Those diagnosed as having an illness are likely to focus on not just what they themselves think they are but also on the meaning of the condition diagnosed for them, i.e., the box into which their identity is stuffed: “What does schizophrenia mean? Does it mean I am not normal? Will I be accepted by my family, friends and relatives? Who am I? What is my identity?” If one is constantly pushed into a subject position defined by highly respected experts one is likely, depending on the degree and threshold of one’s vulnerability, to gradually ‘become’ what is stipulated by that subject position.

The terminological marking and exclusion of part of humanity as ‘schizophrenics’ is likely to undermine the confidence of the excluded and contribute to erode their self-expectations. In this perspective, one can pose the following question. If the word schizophrenic or a similar word or expression had never existed would discrimination be any less? Probably yes as when there is no conveniently definable target it will not be easy to discriminate because there is no group to single out or category to brand linguistically. Lacan (1981) believes that identity and subjectivity are constructed by the ‘symbolic order’ i.e., language which exists before we are born. As we enter the symbolic order we position ourselves in a pre-existing linguistic entity, a subject position. Taking place in the symbolic order, i.e., inserting oneself into the meaning of a subject
position shapes our subjectivity. Language is determining and pre-existing though we can perhaps change subjectivity imposed by language by changing the language terms which construct that subjectivity or by placing different values on a given subject position of the 'symbolic order' in contrast to others. Extrapolating from Lacanian thought one can argue that, if the word X is the only word in the symbolic order designating someone developing a given illness, then everyone having that illness takes on the meaning X. As such his or her identity would be constrained by the subject position, i.e., the linguistic entity available for him/her in the symbolic order. One can propose that Lacanian thought at least in this respect converges with Whorfian theory in that the available subject positions, i.e., language with its words or meanings, set limits to people's perception of the ill person. Also, there is the implication in Lacanian thought that re-valuation (possibly reclaiming, attributing positive connotation) can modify the meaning and thus the value of the subject position in the symbolic order. This leads to the consideration of discourse-based revalorisation as an anti-stigmatisation tactic.

3.1.7 Language and Anti-stigmatisation Tactics

Oppressed minorities, including those with an experience of schizophrenia and their advocates are likely to use the following linguistic tactics in order to promote a positive self-image and as defences against stigmatisation:

1) Metalinguistic tactics
2) Matter-of-factness
3) Denial
3.1.7.1 Metalinguistics tactics

To analyse meaning in relation to lexical structure and/or etymology or grammar is what is defined as metalinguistics (Cameron, 1992) and can be used in de-stigmatisation. Metalinguistic analysis is a form of resistance to the status quo, based on facts of language. It uncovers submerged elements of language. "It shows that people who insist 'that's not what it means' or 'you can't say that' rest their case not on the facts of language, but on the arrogance of power" (Cameron, 1992, p. 112). Metalinguistics looks at linguistic features of words and phrases and questions their meanings, implication and status. This would encourage people to reflect actively on the political nature of the discourse imprinted in the choice of morphology and syntax. Yet, metalinguistic tactics are not succinct or immediately accessible to many people and can only target those interested or willing to engage in reading linguistic reports on origins, connotations and implications of words and phrases.

From a metalinguistic perspective there are eight paradigms which favour the above mentioned DSM-IV recommendation about designations for patients who have schizophrenia. The linguistic modifications of the word 'schizophrenia' can represent particular cognitive or emotional states of speakers and or influence concepts retrieved by hearers. To understand how messages on the speech channel reflect or affect emotional or cognitive states we ought to consider the following...
paradigms:

1. When a modifier goes before a noun, it characterises the noun and says something about the way the noun 'really is'. When it follows, the 'really is' quality is neutralised. *The corner house* is the house that belongs on the corner; *the house on the corner* could be one in the process of being moved overnight! (Bolinger, 1980). In other words, items placed in premodification position are typically given the status of PERMANENT or, at any rate, characteristic features (Quirk et al, 1985). On the other hand, postmodification can be associated with TEMPORARINESS. *The people ready were picked up* refers to a temporary state of readiness. *The ready people were picked up* seems odd as it implies that being ready is something people have as part of their nature, not just a temporary condition (Bolinger, 1980). *The stars visible* refers to stars that are visible at a specified time while *the visible stars* refers to a category of stars that are in general visible. There is a similar distinction between the temporary and the permanent in *the people involved* and *the involved people* (Quirk et al, 1985). By the same token, we could explain that *schizophrenic patient* gives an impression of permanency that *patient having schizophrenia* or *patient with schizophrenia* would not.

2. Certain suffixes such as *-ic* can load some of the connotations of the noun base to which they are affixed e.g.: Artist (who can be a good or bad artist) ⇒ *Artistic* (loading of positive connotations); Trauma (which can be a minor or major trauma) ⇒ *Traumatic* (loading of negative connotations). Webster Third New International Dictionary of English Language (2000); Oxford English Dictionary (1994); Marchand (1969) and Issit (1983) have all failed to notice this property of *-ic*, nevertheless, Quirk et al (1985) briefly mention that the suffix *-ic* can express "an unusual degree or amount." The loading effect seems to be also working in words such as *syphilitic,*
parasitic or schizophrenic. Syphilitic does not always solely mean 'a person who has syphilis'. It more commonly suggests 'a person who is rather severely afflicted with syphilis with all its other possible connotations'. A similar explanation can be offered for schizophrenic. Thus, the word schizophrenic could be commonly considered as marked through semantic loading in the same way that the people it designates can be marked through stigmatisation. Indeed, in this case the process of semantic loading could be the instrument used to represent, translate and communicate, at a linguistic level, the emotional load of stigmatisation at an interpersonal level. One can propose to call this phenomenon 'the linguistic noise', the signal representing an emotional load 'somewhere down there'.

3. The use of -ic can create a distancing effect when it suggests a class or category especially in plural forms: e.g. mystics, fanatics, hysterics, lunatics, spastics. (Recently, the Spastics Society in Britain voted to change its name to SCOPE because members felt 'spastics' had become a term of abuse).

4. Another important aspect of semantics of labels seems to be related to adjectives used as nouns. An adjective used as a noun e.g. a schizophrenic, may rob the individual of his other aspects as it subsumes personhood and agency into illness. The expressions patient with schizophrenia, or patient suffering from schizophrenia may have the quality of first attesting to the personhood or patienthood of the individual and then to his or her affliction. A noun OBJECTIFIES in a way an adjective would not. As Bolinger (1980) mentions an attribute may come and go. If we are frustrated at Jane's lack of appreciation we can refer to her as a person who is ungrateful, or emphasise it and call her an ungrateful person. But when we call her an ingrate we brand her: the noun implies that people like this are in a class by themselves. Another
example given by Bolinger is the connotative difference between a Jew, a Jewish person and a person with Jewish background. On this basis one could propose that using schizophrenic to speak about a patient with schizophrenia may load the conversational dice as it is laying the illness on the personhood. These inherent linguistic connotations can be picked up by the general public including the patients themselves.

5. The difference between having schizophrenia and being schizophrenic is not simply created by the presence or absence of -ic but also by what Fromm describes as the difference between to have and to be (Fromm, 1973). There are suggestions of more possibility for change when you have something (as you can perhaps be cured of it, discard it, lose it or get rid of it) than when you are that something (as you have to change yourself, to develop and be transformed into a new being).

6. To refer to someone as schizophrenic is to handle causality and agency in a completely different way than to refer to the same person as someone with the experience of schizophrenia. In the first case there is a suggestion that the person is ‘passively colonised with the illness’ or ‘done with’ while in the second case there is the suggestion that the person is the active agent and holder of an experience.

7. Bolinger (1980) hypothesizes that we are more likely to link a value judgement to a result than to a process. For example, to grow is a process, growth (tumour) a result. To lose is a process, a loss is a result. In the same way, one can propose that having schizophrenia is a process and schizophrenic a result.
8. When a speaker uses a semantically loaded derivative, the response produced by the word would depend on the characteristics of the audience. Depending on his hearers, various emotionally loaded connotations or a more denotative sense will be activated. Will the phrase *kingly behaviour* generate the same response in a member of the Indian Congress Party, a US republican, a royalist Briton (Issit, 1983) as in a professor of History? Will the word *manly* be received equally by a feminist advocate, by a member of a macho group as by an expert in Social Psychology? Will the phrase *a strong male schizophrenic* generate the same response in a group of psychiatrists as it would in the members of households living in prosperous suburbs? The possible frightening or pejorative connotations of *schizophrenics* may be suppressed when a psychiatrist uses this word in communicating with other psychiatrists and the same connotations activated when another person using the same term addresses the public. As Kempson and Quirk (1971) mention certain linguistic forms can have one or more semantic features that can be regarded as 'latent', i.e. susceptible of being activated in certain contexts and suppressed in others.

3.1.7.2 Matter-of-factness and education

This is another anti-stigmatisation tactic which attempts to muffle the stigmatising impact of certain designations. One can imagine a person who, at an appropriate moment, in the course of an ordinary 'chat' at the dinner table would calmly and simply say that he is 'a schizophrenic'. This is a variety of reclaiming in which at least neutral attributes are implied for the condition. The mere straightforwardness and openness are likely to lead to an infusion of honesty and trust in the relationships. The fact that the person would genuinely own his or her stigmatising condition is likely to demystify and dedramatise the condition. In a sense, avowing to having
something “horrible” would put the person in the position of someone candid who is likely to tell more about themselves, their thoughts and private life than an average person.

Nevertheless, the person deploying matter-of-factness would risk jeopardising his or her relationship with at least a number of those present. He may then wish to educate others about the illness. Yet, some people may already have started avoiding a person who ‘quietly shocked them’ by owning his or her stigmatised condition in a matter-of-fact manner. Others may become over-involved, yet others are likely to get interested and want to know more about the person and provide unobtrusive support if requested and this may attenuate stigmatisation. Consequently, openness about one’s stigmatised condition can at times function as a successful defence tactic against stigmatisation.

3.1.7.3 Denial and secrecy

This is a non-confrontational means of protecting oneself from stigmatisation. It is a variety of linguistic intervention leading to what can be described as ‘absence of a stigmatising lexicon’. The denial of having a serious illness such as schizophrenia, similar to the negation of any other stigmatised condition comes from the desire to be assimilated into the mainstream of the society in which one lives. As long as stigmatisation persists and other methods of de-stigmatisation are either unavailable or ineffective, the stigmatised might resort to silence as a means of defence and self-protection. In its extreme form, the person is likely to go up to dissimulating the stigmatised condition from relatives and medical establishment with consequent drawbacks for themselves and the community.
Denial may lead to the guilt of being dishonest and some sense of falseness and similitude. Nevertheless, the alternative, i.e., the disclosure of one’s stigmatised condition is perceived as leading to a situation in which one is not ‘on a par’ with others. Thus, denial gets justified by the person as a tactic for self-preservation and the guilt may recede.

On occasions, denial will not work as any alternative interpretation of one’s actions may be considered by others nearly as bad as the stigmatised condition. For instance, if people manage to deny their history of schizophrenia, and be truthful in other respects, the narrative of their misery would still emerge. A person who is recurrently absent from work (indeed because of recurrent hospitalisations) cannot continue to make up excuses without being in the end at risk of being considered ‘eccentric’, ‘odd’ and ‘lazy’.

Denial, as an anti-stigmatising tactic is extensively used by minorities for fear of being chastised by the majority. When American diplomats were taken as hostages in 1979 in Iran, Iranian students studying in American colleges and universities were stigmatised as ‘terrorists’. Some had to flee away to Canada; others started to introduce themselves as ‘Turks’, ‘Greeks’, ‘Kurds’ or even ‘Italians’, etc., to Americans who did not know them. As such they had to deny their nationality in order to self-protect from stigmatisation.

Denial and secrecy have the drawback of protecting oneself without tackling stigmatisation. Also, as Link et al (1991) show these instances of defence against stigmatisation (secondary deviance) can produce more harm than good and this is especially so with respect to withdrawal and avoidance.
3.1.7.4 Declaration of solidarity

Solidarity can show itself in discourses such as “schizophrenics are my mates”; “we are schizophrenics”; “I call them friends.” These comments are frequent in the circle of patients with schizophrenia attending meeting with fellow patients at MIND, SANE, NSF (National Schizophrenia Fellowship) and similar advocacy organisations. Solidarity is likely to enhance self-esteem and promote feelings of self-protection from stigmatising attitudes and practices. The solidarity discourse was found to be common in the explanatory responses of patients in my survey as it was the case with matter-of-factness, denial, linguistic intervention and reclaiming. Solidarity as a defence against stigmatisation will be discussed in more detail in the chapter on patients and relatives’ discourse.

3.1.7.5 Reclaiming (Transvalorisation)

Reclaiming is the current term for a tactic that resists the effect of social stigma attached to a name through using it in such a way as to assert positive attributes for it. However much its effects, reclaiming is likely to be cost-effective as it only uses the limited material at hand. To take pride in a hitherto pejorated term is indeed another variety of linguistic intervention which challenges negative attitudes and invites solidarity from both the in-group and the sympathetic outgroups. An instance of reclaiming by African Americans would be for them to use the term ‘black’ to refer to themselves, asserting “blacks are beautiful” and thus reconstituting a positive image for ‘the black’. The movement for the deaf in the United States (Sacks, 1989) is another example: “The deaf are intelligent”, or “We’re proud of being deaf.” Feminists such as Daly
(1978) reclaim the word ‘spinster’ by defining it as “a woman who refuses to yield to patriarchal
society.” It is likely that investing a term with positive connotations would compensate for the
effect of the attached stigmatising meanings and may lead to reinforcement of in-group solidarity
by means of proclaiming shared dignity, courage and resistance. A group of patients with
schizophrenia may reclaim: “Being put through such a trying experience we are courageous
going along with our lives. We are schizophrenics and we are proud of it. Schizophrenics are
brave.” (See chapter on patients’ and relatives’ discourse). In such a context the word
‘schizophrenic’ would almost have the connotations of something ‘heroic’ and the suffix -ic
imparts positive overtones. By the same token, patients with manic depression could reclaim
“We’re creative. We have an artistic spirit.”

Reclaiming is likely to lead to self-empowerment, more autonomy, self-esteem and feelings of self-
respect in the stigmatised. Estroff (1982), reporting the narratives of patients with schizophrenia
whom she and her colleagues studied, refers to what she called ‘normalising talk’ by patients. The
normalising talk attempts to persuade others that the patient is worthwhile, one of us — normal.
This is indeed nothing other than reclaiming value and dignity for schizophrenia, this time not by
a single word, but by a narrative.

Reclaiming has a rather disarming quality in the sense that out-groups are disempowered. They
would not know how to react to those who reclaim a designation as reclaiming would not leave
any neutral corner to which they can retreat. On facing people with hearing difficulty who proudly
declare that “the deaf are intelligent” others would be in a weaker position whether to refer to
them as ‘deaf’ or insist on calling them ‘hard of hearing’. If they refer to them as ‘deaf’ the
addressees have not already authorised the outgroup to do so even if they have chosen to refer
to themselves as ‘deaf’. If people refer to them ‘as ‘hard of hearing’ the addressers have ignored their reclaiming and owe them something for the lack of recognition.

3.1.7.6 Linguistic intervention

The basic tenet of linguistic intervention is that one can challenge the essence of reality that society, science or culture imposes on us. The secret is to put under question. Things are not necessarily the way they seem to be and words do not necessarily imply an unchangeable order. The function of linguistic intervention is to find a vocabulary which can begin to indicate what is happening to the stigmatised and to change their relationship to the world.

Among its other applications, linguistic intervention is used nowadays as a defence mechanism against stigmatisation. Linguistic intervention “is not a neutral review of meanings. It is an exploration of [a] vocabulary...which has been inherited within precise social and historical conditions and which has to be made at once conscious and critical — subject to change as well as continuity...not as a tradition to be learned, nor a consensus to be accepted...but as a vocabulary to use, to find our ways in, to change as we find it necessary to change, as we go on marking our language and history” (Williams, 1976, pp. 21-2).

An example of linguistic intervention is that promoted in relation to the black minority in the US. The term black has negative connotations as can be seen in terms such as blackmail, blackout, black market, blacksheep, blackball, black economy, Black Death, Black Maria, Black Mass, black eye, blackguard, black-head, black hole, black humour, black ice, blackleg, blacklist, black
magic, black widow, blackspot, Blackshirt etc. Neutral words such as blackboard, blackcurrant and positive expressions such as 'to be in the black' are in minority. Romaine (1994) reports that the deputy chairman of the Commission for Racial Equality, who is an Indian, recently estimated that only about 10 percent of Asians in Britain identified themselves as 'black' and about 70% resented the term 'black' applied to them. An example of linguistic intervention in the US consists of using the designation African American for the 'black' minority. This acknowledges their belonging to America and their nationality as American and also refers to their origin as a means of further defining their roots and identity. A similar suitable term for Indians in the UK may be Indian British or Asian British. Another example of linguistic intervention would be to promote 'people with an experience of schizophrenia' instead of 'schizophrenics'. The question whether this is a mere change of name or a more fundamental intervention is going to depend on the discourse associated with it (see below).

3.1.7.7 Motivations for linguistic intervention

There are at least five motivations for the campaigns against the use of the name of an illness as a designation for an individual:

1) All language planning aims to influence thinking and behaviour. The Orwellian hypothesis proposes that linguistic choices influence thought and behaviour so linguistic intervention is likely to influence social behaviour.

2) Some language forms may undermine the confidence of patients already weakened by having
developed a chronic disability. The use of abusive and distancing terms is likely to offend some patients. People with schizophrenia might be more fragile and vulnerable to whatever could persecute them including the feeling that their lives are influenced by others’ words or actions. Linguistic intervention is then likely to boost the self-esteem and confidence of these people. Removing stigmatising terms prevents offending them and is demonstrative of sensitivity and respect of the speaker for their feelings.

3) Linguistic intervention acts as a consciousness-raising device reminding hearers of their underlying assumptions. It is an invitation to revise one’s personal attitudes and remain wary of stigmatisation and discrimination.

4) Linguistic intervention can be used to mobilise support for a political or social movement, assert the legitimacy of the cause and promote the social status of the protagonists. In relation to the latter, the use of the admittedly cumbersome phrase ‘person with experience of schizophrenia’ instead of ‘schizophrenic’ is a policy which symbolically allocates a new and probably more just status to patients. As the analysis of patients’ discourse suggests, patients have different linguistic preferences (see chapter on patients and relatives’ discourse) so mental health workers and patients can discuss the latter’s individual choice as a means of showing respect for the patient’s wish and establishing therapeutic rapport.

5) Linguistic intervention is also a discourse patients use to empower themselves. Disability at some level is determined by how one defines and conceptualises one’s condition. “Persons with comparable illness severity manifest different levels of disability depending on how they conceptualise their problems...Illness may be defined so as to make the condition central to one’s
identity or more peripheral" (Mechanic et al, 1994).

It could be argued that linguistic intervention in describing a patient as 'a person with experience of schizophrenia' instead of 'schizophrenic' is trying to minimise what is happening to the patients and society's responsibility for it, enabling people to take a certain emotional distance from the social reality of the life of these patients. By the same token, it may be argued that using 'a person with an experience of schizophrenia' instead of 'a schizophrenic' is a merely cosmetic change which would drain social discontent into a harmless channel sparing fundamental political and economic structures that promote inequality, as such creating an illusion of progress. This argument sounds justified if linguistic intervention is defined and communicated as a mere demand for 'kinder words'. Indeed, recent changes of terminology have been sometimes determined simply by a discourse marked by common sense 'humane' concern. Though linguistic intervention can be deployed as a powerful discourse in support of the stigmatised, it would turn into an instrument in the service of stigmatisers if it is satisfied with just a change of names in order to keep the stigmatised content. To prefer the use of 'people with an experience of schizophrenia' as opposed to 'schizophrenics' will not be mistaking linguistic symptoms with the social reality of the lives of these patients if it is associated with intervention at the level of social structures as well.

The type of discourse inherent in linguistic intervention should contain an invitation for reconsideration of underlying attitudes in the context of a wider political, economic and social struggle against stigmatisation. De-stigmatisation must be active at the level of individual consciousness as well as that of legislation, social policy, economy and social structures. Linguistic intervention should be an attempt to impose a new order on social relations by means
of language and not on just language. This attempt consists of introducing a line of discourse which has to compete and come into struggle with other lines of discourse in order to shift the ideological and political stances in society significantly. This discourse should tend to rectify the constraints that stigmatisers' discourse exerts on thoughts, perceptions and socioeconomic conditions and provide people with a new instrument to communicate rejection of the existing orders of discourse and to reconstruct a new order through a variety of practical interventions.

Although language can reflect reality and can reshape and re-construct it, it is by no means the only cause of reality. Reality may be contributed to by social, political, biological and environmental constraints in the absence or in addition to language so the latter should not be privileged over everything else in projects for social intervention. Any over-emphasis on the role of language is strategically unwise as what would be easier for a power-holder than to say "You prefer me to call them schizophrenia-sufferers? Granted. I will! But I'm not going to live next door to them or employ them!" The under-emphasis is also unwise as it would ignore the likely constraints that language exerts on human thought and disregard the importance of people's everyday language as a port of entry to the re-examination of their own political attitudes.

Linguistic intervention is a tactic for making a meaning conscious and salient and, at the same time, empowering the stigmatised and asserting possibilities for change. It is to make people aware of non-neutrality of language and provide them with more political consciousness for further action rather than be satisfied with a mere change of usage which would divert attention away from the social and economic infra-structure. It is a prompt for attracting attention to social reality and the need for political fight and, in doing so, helps the public take notice of what they do everyday, i.e., speaking as a means of engaging them in debates about prejudices hitherto
unnoticed (Cameron, 1995). It is a tactic of scratching at the surface while always aiming at the core, a method of challenging people, the media, educational institutions, lexicographers, publishing houses, etc. and catalysing debates which involve people in a discourse of value with the intention of allowing prejudiced ideas to be shaken up and changes in attitudes to be promoted. The debate on a ‘problem’ in people’s language is likely to attract attention to something more malignant in social relations.

Irrespective of who employs it, linguistic intervention challenges and invites at the same time: challenge to whoever resists the idea promoted and invitation to whoever might be sympathetic enough to the idea to join. It is a political rank making and recruitment, inviting a new way of thinking about social relations, proposing a new political stance, setting the agenda for future actions and challenging those who are intolerant or insensitive to its messages. The tactic of linguistic intervention is to declare the presence of alternative stake-holders and pressure groups and to invite interlocutors to consider those alternative attitudes. It proposes sociopolitical alternatives which, by opening the way to new discourse routes, have as aim to split and fragment the opponents. At the same time, linguistic intervention provides patients with a new message about their ‘self as reflected in others’, i.e., their reflective self-concept and this would act as a new discourse in the dynamics of social orders of discourse available to patients about their social value, responsibility, and agency and open the way for their feelings of well-being.

Cheshire (1984) relates recent changes in sexist language, e.g., the reduced use of masculine generics to an improvement in the social position of women which language mirrored (and, indeed, enacted). The discourse which favours the use of non-sexist language both reflects and enacts the reality of change in the social position of women. The issue of the use of ‘a person with
"experience of schizophrenia" instead of 'a schizophrenic' is a question about both the representation of the speaker's relation to the individual who is ill and also the enactment of a new relationship by means of that discourse. Although calling people who have schizophrenia in one way or another cannot totally resolve, on its own, discrimination, problems with employment and integration these patients face, it proposes an alternative discourse which both reflects the growing efforts at integrating these people, promotes reconstruction of the value of patients as a first step towards their gradual empowerment and enacts a political function. Yet, this enactment is not the same as sorting out problems with employment, discrimination, etc. It is a step towards them. Other enactments have to follow for the discourse to build up into more widespread social action.

Discourse is not always in the form of language and de-stigmatisation is not just a matter of changes in language. The discriminatory component of the stigmatising attitude can be non-linguistic: segregation, distancing, depriving, coercion or confinement. Yet these are enactment of some underlying discourse and are themselves discourse. Discourses can come in chains of ever expanding related discourses. A linguistic discourse can lead to here a discourse enacted legally there to a discourse enacted politically. There is always a potential in concentrating upon one discourse, i.e., one aspect of a social process of seeming to reduce it to that aspect alone. In the words of Fairclough (1989, pp. 233-4): "One must not reduce emancipation to 'seeing through'...Even while we focus upon language... let us remind ourselves that social emancipation is primarily about tangible matters such as unemployment, housing, equality of access to education, the distribution of wealth, and removing the economic system from the ravages and whims of private interest and profit."
Linguistic intervention is not uniquely a weapon used by the stigmatised, their advocates and those on the left of the political spectrum. Contrary to prevalent views which attribute linguistic intervention, or so-called 'political correctness', to left-wing factions, it is extensively used by power holders despite their attacks on it when it is practised by the disinherited. Power holders systematically deploy linguistic intervention with the same aims as the stigmatised: offering alternative ideologies to adopt, challenging the present one and constructing a new discourse. For example, during the Gulf War in 1991 the allied forces decided to use the phrase 'collateral damage' to describe the killing of civilians in military attacks on Iraq. 'Collateral damage' was used as a way of minimising the affective impact of a more direct and objective description in terms such as 'incidental killing of women and children.' By circumventing emotionally loaded words the allied forces' spokespersons attempted to lessen the emotional impact of killing of civilians and solicit alternative attitudes towards them. The engineered linguistic facade works on people before they get to 'repair' their understanding by cognitive work (supposing people would systematically make such effort).

Cameron (1995), though asserting the power of linguistic intervention in challenging stigmatising attitudes towards women, misses the idea (p. 72) that the use of 'collateral damage' is indeed a similarly powerful example of linguistic intervention used this time by those in power to blur the emotional impact of a more direct wording of the facts. She falls into the trap of asserting that this would not change anything in the impact of the news on the hearers, and she does so as an attempt to criticize Orwell (1946) who believes that language needs to be direct and free of euphemism. In doing so Cameron contradicts herself as elsewhere (e.g., p. 142) she expands on the idea of how much can be done to attitudes through linguistic intervention. 'Collateral damage' is an example of the use of a discourse by those in power trying to divert social protest in the
West about the war (irrespective of whether or nor that war was justified in the first place). This is how linguistic intervention could be used to dampen down possible resistance or public discontent. There are numerous other examples of this nature for example the practice of naming the atomic bomb detonated over Nagasaki as ‘Little Boy’ and that over Hiroshima as ‘Fat Man’. The choice of vocabulary and grammatical structure presents the mind with reality from a particular angle, giving it a particular shape, meaning and significance. It thus creates a new discourse.

The use of linguistic intervention by stigmatisers and power holders is important as any attempt by the stigmatised in introducing an anti-stigmatising discourse is likely to be opposed by a countervailing stigmatising discourse re-introduced into the public order of discourses and at times even colonising the original anti-stigmatising discourse. An example is the assertion by some that “Victorian hospitals must be re-opened to accommodate ‘schizophrenia sufferers’”!

This appropriation and corruption of discourse of advocacy organisations (schizophrenia sufferers) by power-holders is by no means an isolated example. A given designation can be used by both those in power and the stigmatised in such an attempt to create a different discourse. For example, the term ‘sex worker’ can be used by a prostitute to declare her job when she is questioned about it, in order to request a less morally stigmatising attitude towards herself without necessarily implying that she considers her ‘work’ on a par with other varieties of economic activities. The same formulation can be used by a pimp (who exploits and stigmatises the prostitutes) in reference to the latter to suggest that he considers his enterprise an economic activity as professional as any other business. He then goes up to calling himself ‘sex manager’ further asserting that he is one of those stakeholders considering prostitution to be an industry.
Mass communication networks are likely to propagate discourses to promote the cause of the disadvantaged when these discourses are embedded within a larger discourse in the service of the state or power holders. Within the already established social structures "members of the high status group.... control various institutions of the communication network" (Labov, 1972, p. 179) and “given the nature of the hegemony of the dominant group, one does not need a conspiratorial theory to recognise that the dominant group is unlikely to subscribe to enhancing the situation of the subordinate, without when necessary, simultaneously guaranteeing or strengthening its own position” (Williams, 1992, pp. 132-3). This argument seems plausible given the extent of struggle for power among different social fractions (Dahrendorf, 1959) yet it becomes questionable when it is applied to intellectuals and advocates in positions of power. Cooper (1989) argues that language planners are the first beneficiaries of their efforts, for example, the feminist campaigns against sexist language enhance the influence of those academics and writers who can show others how to avoid sexist usages. The counterargument one can propose is that nothing prevents people enjoying satisfactions related to an intellectual or social activity while the repercussions of the latter are, at the same time, of benefit to society. Cooper continues “to the extent that the cooperation of the mass is a prerequisite for the maintenance of the elites and to the extent that benefits to the mass encourages cooperation with the elites, the latter are well-advised to channel the benefits to the former or at least give the appearance of doing so” (Cooper, 1989, p. 83). One could respond to this recommendation by arguing that the invention of electric bulb or the discovery of universal attraction did not need to “channel benefits” to the mass or “give the appearance of doing so” as the latter have actually benefitted the mass while they have of course benefited inventor and discoverer as well. It is the degree of our belief in the genuineness of language planning that tells us if we can categorise the latter with other human or intellectual efforts which have been of benefit to human societies. Indeed elsewhere Cooper (1989) mentions
that if language planning serves the elites it may also serve the mass, particularly in so far as it strengthens the individuals’ sense of dignity and self-worth.

One can add that indeed language planning can be initiated by the disadvantaged like patients with schizophrenia themselves when requesting not to be called ‘schizophrenic’ as is clear from the publications of organisations such as MIND and confirmed by the results of my survey. When someone introduces himself as ‘Robert’ it is an odd, annoying or even hostile act to insist on calling him ‘George’ (Cameron, 1995). In modifying names originally given them by others, patients are asserting their right to be called by a name of their own choice and create their own emancipatory discourse.

In summary, linguistic intervention, as a defence tactic against stigmatisation is discourse, i.e., social practice and its significance is determined by its content as a discourse. For it to be effective it should be only one aspect of a multi-dimensional tactic towards de-stigmatisation which acts both at the level of individual consciousness and of social institutions.
CHAPTER IV

AN ASSESSMENT OF STIGMATISATION IN PATIENTS WITH SCHIZOPHRENIA AND THEIR RELATIVES
4.1 Stigmatisation of Patients with Schizophrenia

4.1.1 Introduction

The significance of stigmatisation at the start of the twenty-first century is not exactly what it was in the 1960's when Erving Goffman in a study in Berkeley was developing his thoughts on stigmatisation under a grant from the President Committee on Juvenile Delinquency. Today in the more advanced modernist era, an epoch of cyberspace, websites and real-time electronic communications, we are bombarded every day with signals and images. Anxiety about the possibility of being submerged by an ever-increasing influx of new data makes us codify, classify and categorise now more than ever in human history. To save on valuable reserves of memory and perception, we are driven to understand, decode and process as economically as possible. As such there is a danger of missing in-depth or quality understanding. Though the latter are highly valued, they are allowed to be sacrificed for pragmatic or cost-effective reasons or achieving quantitatively defined targets. The pace of the world events, the explosion of data, the development of ever-speedier processors, imaging and communication techniques, procedures for compression, transformation and quantification of information means that the human mind is under demands more stringent than those of the mid-twentieth century. In such an atmosphere, it may not be seen as 'efficient' to find out, e.g., whether a person with mental illness has qualities over and above what the name of their illness implies. If in the 1960's the word 'schizophrenic' brought to the mind a stereotypic concept of a 'mad' person to the exclusion of their other qualities, in this epoch the same word is likely to have a real-time translation into a visual stereotype because "cameras don't lie." The news of a sporadic killing by a patient with
schizophrenia is no more the news of the village, town or province where it happens. It is
instantaneously multiplied by the number of TVS, radio sets and cyber news stations. Compared
to few decades ago, there are more television sets, TV channels, sensationalist programmes and
broadcasting times. As such the above news is likely to immediately reinforce not only our
semantic stereotype of schizophrenia but, as it is presented along with images, its visual
stereotype, making it even more concrete and immediate.

While a number of previous conceptions of stigmatisation are still valid, at the start of the twenty-
first century we are in need of a new or at least revised theory of stigmatisation suitable for
understanding a phenomenon which is taking more and more importance not only in relation to
racism, ageism and sexism but also as one of the most important impediments to the treatment of
patients with a diagnosis of a mental health problem. Delayed help-seeking and non-adherence to
anti-psychotic medication are among afflictions of community psychiatry today. Twenty-first
century patients are acutely aware of the phenomenon of stigmatisation. Television has
revolutionised entertainment even for patients. Today a good number of people with
schizophrenia say “I don’t want the schizophrenic tablets.” Patients are likely not to accept
medication of course for the inconvenience of continuously adhering to a treatment regime and
the associated physical side effects but also other side effects — by taking the medication, they
would inevitably endorse the idea that they are ‘mad’.

It was Kraepelin (1896) who put together symptoms subsumed by the diagnosis of schizophrenia
under a single category ‘dementia praecox’. Eugen Bleuler (1955) renamed the condition
“schizophrenia” in order to stress the ‘splitting’ and disintegration of personality as its most
important characteristic. In clinical practice, patients with schizophrenia constitute a
heterogeneous group and the concept itself does not consistently relate to any unique biological entity (Tsuang et al., 1990), is used in different ways by different psychiatrists, and some ethnic groups (e.g., African-Caribbeans) are much likelier to receive the diagnosis (Littlewood & Lipsedge, 1982; Harrison et al., 1988). Faced with behaviours which are disturbed and strange, clinicians and the public easily fall into the trap of opting for the designation ‘schizophrenic’ which thus has become a blanket term to cover almost everyone who has a disturbed behaviour. There is also a tendency among psychiatrists to misdiagnose mania for schizophrenia (Egeland et al., 1983) partly because of sometimes overlapping symptomatology of mania and schizophrenia.

One of the major factors motivating stigmatisation of schizophrenia is the fear of violence by patients. Yet, only a small minority of patients with schizophrenia commit violent crimes (Torrey, 1994; Wessely, 1997; Eronen et al., 1997). Though the majority of patients with schizophrenia do not commit violent crimes, stigmatisation is based on the principle of self-interest (see chapter entitled “Unitary Theory of Stigmatisation”) so people tend to avoid the small additional statistical risk of becoming the victim of a violent crime, by writing off en masse the population of patients with schizophrenia — the latter’s rejection as a group being the cost of people protecting themselves from the very small minority of patients who commit violent crimes.

4.1.2 Management of Stigmatisation in Schizophrenia

For reasons described later, is not uncommon for a patient with schizophrenia to present disturbed behaviour or appear in a dishevelled state in public. The behaviour is not necessarily interpreted by the public as a sign of schizophrenia per se, rather as the sign of some ‘oddity’, ‘eccentricity’
or ‘madness’ causing discomfort, fear or uneasiness in the observers, leading to stigmatisation. In this sense schizophrenia can be ‘visible’. The visibility is not universal in patients and a number of those who are properly treated would not show any indication that they are different from other people though in some long-term afflictions, a number of residual disabilities such as occasional gesturing or muttering may persist. The side effects of the use of anti-psychotics can be present in the form of severe trembling, orofacial grimacing and choreoathetoid movements. Especially for the medically informed, these are possible signs of usually protracted treatment with antipsychotic medication. This and similar obtrusive symptoms are likely not to allow the stigmatised to keep their condition a total secret. All the same, residual symptoms are usually much less visible or obtrusive than the presentation of the untreated illness in which hallucinatory behaviour, perplexity, apathy, incongruity of affect, and in certain cases catatonic posturing, can be prominent. This means that the obtrusiveness would depend on the stage and type of the illness (in remission, moderately well treated, resistant illness) and the type of symptoms concerned (agitation, hallucinatory behaviour, socially inappropriate behaviour, catatonic posturing, thought disorder, etc.). The ‘perceived focus’ in schizophrenia concerns both personal relationships (stigmatisers are likely not to want to marry the patients) or work performance (it is less likely for a patient with schizophrenia to obtain employment). This suggests that if the illness is visible or known about, both social and employment chances of these patients are likely to be jeopardised.

A considerable number of patients with schizophrenia are not treated, at least adequately, partly because of their fear of stigmatisation if they were to reveal the illness, partly because of the denial (which is likely to be, at least in part, related to stigmatisation), and finally because of poorly coordinated community care in psychiatry. The results of most long-term studies of outcome in
schizophrenia suggest that only up to a third of patients have a good prognosis. Manfred Bleuler’s studies (1972; 1974) showed that twenty years after admission, 20 per cent of the patients had no symptoms and 24 per cent were severely disturbed. Ciompi’s (1980) follow up of patients over an average of thirty-seven years showed that about 30 per cent had good or fair outcomes with symptoms generally becoming less severe in later life. Other studies (Huber et al, 1975 and Tsoi & Wong, 1991) reached similar results. In Tsoi & Wong’s study, after fifteen years of follow-up, about one third of the patients recovered but 17 per cent were unable to function outside the hospital. These studies suggest that grossly 30-35 per cent of patients with schizophrenia have a good prognosis, about 50 per cent have moderate prognosis and the rest, about 15 to 20 per cent poor prognosis. Those with a good prognosis are likely to be only occasionally ‘visible’ in stigma terms. Those with a moderate prognosis are likely to have more recurrent exacerbations of their condition with re-emergence of the symptoms, i.e., ‘intermittent visibility’ is stigma terms. Those with poor prognosis are likely to be ‘visible’ most of the time.

Patients are likely to defend themselves against ‘visibility’ by resorting to the tactic of seclusion, isolation and social withdrawal at least partly induced by stigmatisation. These defences against stigmatisation is what the labelling theory calls “secondary deviance” (Lemert, 1967) which accentuates the effects of stigmatisation and has further labelling effects. Even intuitively one can imagine that isolation, seclusion and withdrawal are likely to reduce the degree of social integration and life chances of the patients.

Someone with schizophrenia who is ‘visible’ has to face the stigmatisation but if they are not ‘visible’ they still have to face the possibility of ‘known-about-ness.’ Some of their relatives, acquaintances, friends and neighbourhood are likely to have seen them in one of the disturbed
phases of their illness. Their clinical history can be known to medical, paramedical, secretarial and clerical staff. They may be known to the local chemist who regularly make up their prescription for antipsychotics. They may have shown some ‘bizarre’ behaviour in public and be known to local children, shopkeepers, social workers and police officers. They may be recognised by some patients who were with them in hospital and greeted by them making people who know the other patients wonder whether they are ‘one of them’ too. They may be recognised by fellow patients’ relatives who incidentally noticed them in the day centre or the hospital, by the lay person who saw them in the mental health tribunal, by the social security officer to whom they gave their sick certificate bearing their diagnosis or by the ambulancemen who took them to hospital after they were sectioned. The ‘known-about-ness’ in these cases implies at least the knowledge of previous ‘bizarre behaviour’, ‘schizophrenia’ or ‘psychosis’ but would not exclude doubts and suspicions about him continuing to have the illness at present even though it may not be ‘visible.’ Denial, secrecy, social withdrawal, excessive mobility, anonymity, re-formulation of identity, re-formulation of the diagnosis or emphasis on the somatic symptoms of the illness are some of the tactics patients with schizophrenia and/or their family or carers use to protect themselves or their patients about the ‘known-about-ness.’

In my survey up to three attempts had to be made at finding patients at their registered addresses in the door-to-door survey. It was easier to meet patients in hostels or hospitals as the carer would tell us if a particular patient, randomly selected for the survey, was in. When the patient seemed not to be at home and an effort was made to ask a neighbour when they would return the response at times was that he or she was in but would not respond the door bell. The purely clinical interpretation is likely to be that these patients suffered from persecutory ideations and as such avoided all contacts. There probably is at least some degree of truth in this statement. Yet,
there are other aspects to the truth in that these patients presumably avoided being visible, for fear of being sent to hospital or meeting people who would already know about their ‘stigma’ or even people who would discover their ‘stigma’.

Patients and families are likely to create more and more layers encapsulating themselves in order to self-protect from stigmatisation. These layers are indeed filters they put between their inner world and the outer world — only ‘safe’ gestures, acts or data could be allowed out, those which would not carry the risk of self-revelation, but as there is sometimes no control over what might appear in one’s behaviour it would be better to cut down all contact. Anonymity is also used by carers of the hostels, half-way houses and day centres patients attend. Such centres are commonly referred to as number such, such street, rather than day centre for patients with schizophrenia, which might incite fear, protest or further stigmatisation from the community. Mobility, what sometimes is called ‘rootlessness’, is used by the stigmatised and sometimes their families as a way of escaping old acquaintances, neighbourhoods and communities who already know the person as having schizophrenia, giving themselves a fresh chance for anonymity and control of personal information or the family secret. Re-formulation of identity consists of attempts to change religion, political beliefs or the variety of practice of one’s own religion, or to change one’s own name either for the sake of anonymity or reformulation of one’s identity (for example when the stigmatised changes his name from Jackson to Kingman) or when a neutral name (such as Smith) is used, for feeling better about one’s personal worth by ‘leaving behind’ an already discredited identity. Re-formulation of the diagnosis usually takes the form of referring to the illness as ‘depression’ or request to the medical establishment for a change of diagnosis or investigating organic aetiologies for the illness in order to reduce the associated stigmatisation without denying that the person suffers from some illness. Emphasis on somatic accompaniments
of the mental illness is likely to be used by patients and relatives again as a means of representing the condition as 'non-mental' or physical with its reduced stigmatising connotations.

4.1.3 Links Between Stigmatisation of Schizophrenia and Its Prognosis

4.1.3.1 Fear of stigmatisation, delay in help seeking and poorer prognosis

Stigmatisation of schizophrenia diminishes its recipient's subjective self-worth, reinforces feelings of self-devaluation and appears to exacerbate the clinical course of schizophrenia. As discussed above, the fear of being considered unworthy, useless, undesirable or worthless, in brief, the fear of being stigmatised makes people with mental illness and, at times, their families deny the illness and delay seeking help. Paradoxically, the patients' tactic for avoiding stigmatisation is likely to lead to other varieties of stigmatisation —they are likely to end up having accidents, taking illicit drugs, self-medicating (Byrne, 1997) or committing suicide.

Early intervention would reduce the financial, emotional and human cost of the illness and prevents chronicity and institutionalisation. Stigmatisation of mental illness in addition to all other noxious impacts for the stigmatised has the deleterious effect of making the discredited attribute, i.e. the illness itself worse, leading to another vicious cycle with more stigmatisation, more seclusion, more secrecy and further deterioration.
Avoidance by ordinary people of a person with a contagious disease for fear of contracting their illness would not make the disease any worse but such avoidance is likely to make the mental illness itself worse, by its being left untreated by the patient for fear of stigmatisation. Patients would not just pay emotional costs (which is likely to be the case in almost all stigmatisation) but, in those who avoid treatment because of stigmatisation, the stigmatised attribute itself is likely to get worse. This is an example of the fact that though all instances of stigmatisation have shared aspects there are wide varieties of stigmatisation, each with their own special forms, harmful effects and specific sub-mechanisms.

4.1.3.2 Personal agency and the prognosis of schizophrenia

The prognosis of schizophrenia worsened in Western countries in the mid-nineteenth century, perhaps in causal association with social segregation of patients (Warner, 1994). During the 20th century the prognosis improved considerably (Kraepelin, 1919; Mayer-Gross, 1932; Brown et al, 1966; Bleuler, 1972; Bleuler, 1974; Ciompi, 1980; Huber et al, 1975; Harding et al, 1987 a & 1987 b; Angst, 1988; McGlashan, 1988) the trend preceding the introduction of neuroleptic medications in the 1950s. With few dissenters (e.g., Cohen, 1992) it is generally accepted that schizophrenia has a better prognosis in the Third World. The latter, as found in the World Health Organisation's International Pilot Study of Schizophrenia (IPSS) (WHO, 1973) is partly attributed to social response, particularly to cultural differences in assigning individual responsibility for the illness to patients, i.e. the notion of personal agency (Cooper & Sartorius, 1977; Waxler, 1977, 1979; WHO (1979), Clausen, 1981; Horwitz, 1982; Marsella & White, 1982; Sartorius et al, 1986; Beiser et al, 1987; Scheper-Hughes, 1987; Kleinman, 1988; Littlewood, 1988; Lin &
Kleinman, 1988; Fabrega, 1989; Littlewood, 1990; Jablensky et al, 1992; Littlewood, 1998). As Waxler (1974) mentions: “Many peasant societies, like the Ceylonese, do not ‘make much’ of mental illness. Beliefs centre on external causation, treatments are routinized, and there is no stigma. When a person becomes ill he is believed to be basically unchanged as a person. Families, acting on the basis of these societal beliefs, give explicit and implicit messages to the patient that reinforce the normal role.”

4.1.3.3 Individualism, independence and the prognosis of schizophrenia

Safilios-Rothschild (1970) observes that standards for health and perfection as well as for beauty appear to be very constrained in Anglo-Saxon countries, especially among the middle classes, with any deviation from the highly admired state of perfection being punishable by social stigmatisation. As such the individual is considered significantly responsible for whatever s/he is. As in Western cultures independence is highly valued the overwhelming core anxiety of the individual is a fear of dependency (Hsu, 1972) and, in a person suffering from schizophrenia, this fear, associated with the internalisation of distress and guilt related to the idea of personal agency is likely to lead to chronicity of the illness (Draguns, 1990). Understandably, feelings of dependency are noxious for personhood in societies which encourage individualism and independence and the only remedy which seems to compensate for those feelings is respect, and infusion of confidence, hope and value in the patient. This is how perceptive people with schizophrenia have described some of the social factors that affected their adherence to treatment and even recovery. These include association with people who respected them as persons and showed confidence in their potential for recovery (Leete, 1987).
In less individualistic and more interdependent cultures, a person’s concept of self is more collectively defined in the sense that it is merged with that of the community. This diffuses and dilutes the self-disorganisation experienced in schizophrenia into the collective identity. In the context of the same collective identity, in more traditional societies, the burden of mental illness is shared with informal sources such as local healers, clergymen, herbalists and shamans. Further, inasmuch as trance, possession and other short-term dissociative states are common in such societies, self-disorganisation is considered a temporary condition with less self-evaluation and more intact personal relationships (Lefley, 1994). On the contrary, in more individualistic cultures the self-disorganisation gets concentrated in the individual to a degree that it is more difficult for the afflicted person to distance themselves from the disorder (Fabrega, 1989).

Also, in interdependent societies, the environment for patients having schizophrenia is "supportive and tolerant and [with] little risk of prolonged rejection, isolation, segregation and institutionalisation" (Cooper and Sartorius, 1977). In such societies, patients can work at their own pace in normalised agrarian jobs again usually with little self-devaluation as far as their work is concerned, while in most industrialised countries the emphasis on individual skill, speed and specialisation makes those patients, if at all, usually end up working at demeaning low status jobs (Lefley, 1994).

The above indicates that cultural dimensions such as collective identity and interdependence provide for a lower degree of stigmatisation. This is in agreement with experiments in social psychology in which people working in interdependent co-operative groups with members who have a stigmatised condition would reduce stigmatisation (Blanchard et al, 1975; Desforges et al, 1991; Van Oudenhoven et al, 1996). Also, it is in agreement with Littlewood’s (1998) findings
in Calcutta, a rather interdependent society, which showed a lower degree of social stigmatisation of patients with psychiatric illness. Further, a comparison between patients with schizophrenia in Liverpool and those in Bangalore (Sharma et al, 1998) demonstrated that the Liverpool patients were less likely to be married, more likely to live alone, more likely to be isolated, less likely to be socially integrated and more likely to be marginalised than patients with schizophrenia in Bangalore. This suggests that in more compartmentalised, individualistic, Western societies, where dissolution of traditional families and economic mobility are more common, patients are more likely to find themselves left to their own devices and, deprived of a containing, interdependent relationship, are prone to further deterioration.

The lower degrees of stigmatisation in more traditional, less individualistic and more interdependent societies like that of India is possibly linked to the better prognosis of schizophrenia in those societies.

4.1.3.4 Stigmatisation within families and the prognosis of schizophrenia

The family and those who live in close contact with patients are more likely to be aware of and subjected to the visibility and obtrusiveness of the illness. Family responses to patients diagnosed as having schizophrenia have been shown in a number of studies to affect the clinical and social prognosis through interpersonal communication, conceptualised as Expressed Emotion [EE] (Brown et al, 1962; Vaughn & Leff, 1976; Leff & Vaughn, 1981; Leff et al, 1987). Nuclear families in the West are considered to be less accepting of mental illness than are extended families in some other cultures such as India (El-Islam, 1979; Lefley, 1990) and EE which is higher in
Western families (Leff et al, 1987) is associated with stigmatising responses within the family (Greenley, 1986).

EE as an interpersonal pattern in a family with its effect on the prognosis of schizophrenia is likely to be related to "EE in a community", i.e., the emotional components of social rejection and stigmatisation. The family is embedded within a sociocultural system and, as such, EE within families is likely to be linked to the degree of social stigmatisation. The family members, like any other members of society, have already incorporated prevalent societal attitudes. Exposed to the actual effects of social stigmatisation the family is likely to get distressed by the feelings of being socially discredited. Outside families' real difficulties in coping with some of patients' behaviours at an interpersonal level, the shame and embarrassment suffered for the patient behaviours and intensified by social stigmatisation are likely to make the family want to change the situation by increasing the frequency of critical comments against or the degree of involvement with the patient (Greenley, 1986). This would mean an increased level of EE with a consequent poorer prognosis for the patient.

4.1.3.5 Political priority of psychiatry and poorer prognosis

Another link between the stigmatisation of mental illness including schizophrenia and its prognosis is that the former leads to lower political priority in funding clinical services, research and additional therapy for patients. Public opinion would determine political priorities through democratic elections. Law makers, politicians and political parties depend on the public opinion and in most cases have to follow it in order to remain in power but also they are likely to hold the
opinions in the first place.

A poor public image leads to diverting resources to other spheres of activity which are considered as having a higher priority. As Harme et al (1994) points out, the mere expectation of poor services and suboptimal outcome is likely to affect the degree of patients' positive transference towards the services and the outcome of the treatment. A viscous cycle may thus be built up, with negative public opinion leading to low priority given to psychiatric treatment, leading to poor services, expectations of poor-quality treatment, resulting in a negative transference in patients, poorer outcome and further negative public opinions. This is the fourth and final pathway by which stigmatisation leads to poorer prognosis in schizophrenia.

4.1.4 Schizophrenia and Resilience to Stigmatisation

The persistence of negative social attitudes towards patients with mental illness including schizophrenia has been recently demonstrated (Crisp et al, 2000). What can the stigmatised do about the stigmatisation? One could argue that those patients who would behave appropriately, are regarded by people as human, sociable, warm and helpful, may moderate any negative attitudes and be accepted by others. Yet one must consider that patients with schizophrenia have to contend not only with an illness with a strong biological component but also with the social predicament of being considered a 'schizophrenic'. Despite being fragile, vulnerable and ill they are expected to build themselves up again from a shattered identity if they want to establish themselves as persons all over again. To overcome both the real deficit linked to the illness and the pressure of negative attitudes, they may have to possess so many positive qualities that only
a few may succeed so the majority are likely to feel trapped in the identity of 'a schizophrenic'.

The fact that a non-schizophrenic does not have to possess many positive qualities to compensate for preconceived attitudes and patients have to, means that their lives are differentially loaded. They have to fight to prove that they are not their illness. They have to try to be accepted, to prove almost apologetically that they are good people. They would be indeed, at best, on probation by society. They have been discriminated against by the mere fact of the existence of preconceived negative attitudes whether they succeed or not, at last, to fight them off and integrate into society.

If we accept that in the construction of self both intrapsychic (psychodynamic) and interactional factors (such as stigmatisation) are involved it seems plausible that a certain category of assertive persons with high self-esteem could, with the expense of time and energy, open up their way towards integration and social success despite all stigmatisation. All the same, there are varieties of stigmatisation the consequences of which no strong person could avoid. A person from a Jewish background held by the Gestapo and aware that s/he is destined to be killed could hardly avoid stigmatisation. Also, those with schizophrenia whose lower self-esteem has been fragilised as a result of a life event such as the diagnosis of a serious illness and subsequent loss of status would probably succumb to a moderate degree of stigmatisation as there is practically no psychodynamic shield to protect them.

In summary, there is a range of resilience or vulnerability to interactional factors and thus stigmatisation can have a range of different effects on different persons. Vulnerable groups are likely to benefit from efforts made to reduce the effects of stigmatisation. These interventions are
explored in the chapter entitled Routes to De-stigmatisation.

4.1.5 Research on Stigmatisation in Patients with Schizophrenia and Their Relatives

Though there has been a substantial body of research regarding the general public’s and professionals’ attitudes towards patients with mental illness, there has been considerably less research into patients’ and relatives’ perception of stigmatisation towards patients and their own predisposition to enact stigmatisation themselves in relation to schizophrenia. Further, though there are frequent first-person accounts of patients and relatives’ personal experience (e.g., Houghton, 1980) comparatively little effort (e.g., Scheper-Hughes, 1987; Barham & Hayward, 1995) has been made to analyse the content of these patients and their relatives’ discourse systematically.

Yarrow et al (1955) discovered that fear of stigmatisation and rejection and attempts at concealing the mental illness were common in their sample of wives of first admission psychiatric patients. Freeman & Simmons (1961) assessed the feelings of stigmatisation among mothers and spouses of recently discharged psychiatric patients using structured questions which measured the relatives’ concealment and secrecy in relation to the mental illness. The proportion of the relatives responding positively to at least one item on concealment and secrecy was relatively low (about 25%) and so the authors reported that these feelings of stigmatisation were characteristics of only a minority of the relatives of psychiatric patients. Yet, they mentioned that their structured questions could not include those relatives who would not resort to concealment and secrecy even
though feeling stigmatised. Also, about two decades later, Thompson & Doll (1982) used Freeman & Simmons questions with a comparable sample of relatives and discovered that twice as many relatives responded positively to at least one concealment items, nearly 50% of all the relatives. Clausen (1980, pp. 32-33) though attempting to differentiate between ‘negative public attitudes’ and stigmatisation per se reports that in his family studies “the fear of stigmatisation is widespread among the mentally ill and their families” and that “there are very few patients or relatives [spouses] who did not feel apprehensive about others’ reaction to mental hospitalisation”.

Nuehring (1979) measured the extent to which discharged psychiatric patients were seen as a burden by their family and friends. She concluded that there is a moderately high tendency in relatives and friends to consider the patient as a burden. Wahl & Harman (1989) assessed the views of families of patients with mostly severe mental illness who were members of the National Alliance for the Mentally Ill. This is a highly selected group both because they suffer from usually severe mental disorders and so may experience higher levels of stigmatisation and because there is a tradition of active advocacy against social stigmatisation in NAMI. More than 75% of the participants perceived and expected stigmatisation towards their mentally ill relative and nearly 90% reported that stigmatisation was very much associated with mental illness. Phelan et al (1998) assessed perceptions and reactions to stigmatisation in parents and spouses of first admission psychiatric patients. Though relatives did not perceive themselves as avoided by others, half reported concealing the hospitalisation of their family member at least to some degree. None of these studies focuses uniquely on relatives of patients with a diagnosis of schizophrenia.

As far as patients are concerned, Miller & Dawson (1965), Spiegel & Younger (1972), Nuehring
(1979) and Link et al (1989) all reported moderate to high levels of perceived social stigmatisation in patients. Research on the whole suggests that patients' attitudes towards other patients with mental illness is negative (e.g. Swanson & Spitzer, 1970, Weinstein, 1983). Shurka (1983) reports that, in Israel, psychiatric patients express negative feelings towards other psychiatric patients. Yet patients and relatives' attitudes seem to be more tolerant than those of the general public. In a study by Brockington et al (1993) people with personal experience of mental illness including some patients and relatives were more tolerant towards mental illness than those with no personal experience of mental illness.

Again, none of the above studies concentrated on patients with schizophrenia. As Farina (1998, p. 248) mentions there is little research that focuses on the stigmatisation of schizophrenia in particular and when such research is done it is mainly to compare social attitudes towards schizophrenia with attitudes towards another form of disability. It was felt that a more representative sample would allow to draw conclusions with greater confidence than in some other studies with less representative samples. Also, almost all the studies on relatives' attitudes assessed their feelings of being stigmatised themselves rather than their perception of social stigmatisation directed at patients even though these two may be correlated.
4.2  **A Study of Stigmatisation in Patients and Relatives in Camden & Islington**

4.2.1  **Introduction**

The study of stigmatisation in patients and relatives reported in the following chapters seeks to combine a quantitative and/or qualitative examination of the attitudes, wishes, feelings, experiences, explanatory models and defence mechanisms of patients and relatives against stigmatisation of schizophrenia. It was expected that the factor analysis of the results would point to the basic attitudes underlying stigmatisation that even patients and relatives would not be able to avoid despite any conceivable moral, family or other pressure not to stigmatise so these factors were hypothesised to be nearer to the raw core and central meanings of stigmatisation.

4.2.2  **The Target Populations**

Prior to starting the survey the target population of patients was defined as those randomly selected from the list of patients admitted to one of the South Camden and Islington NHS hospitals who personally knew of their diagnosis of schizophrenia for a period of more than six months and who were in remission at the time of the interview. Patients who were 'rootless' probably due to recurrences of the illness and so practically untraceable were assumed not to be in remission though this could not be proved.
The target population of relatives were relatives of patients who were randomly selected from the list of patients. Relatives were included in the survey if they consented and knew of the diagnosis for more than six months and only if the patient had consented that the relative be included in the survey unless the patient was too ill to be consulted, was not traceable or had died. A relative was considered to be anyone the patient, a carer, or the hospital records indicated as relative. They ranged from a son, daughter, sibling, parent, to an uncle, grand parent, stepmother or adoptive father. Some patients did not have any relatives. If more than one relative was available one was randomly selected by a draw from the available relatives.

It was considered necessary for patients and relatives to have known the diagnosis of schizophrenia as otherwise their responses would not have been in relation to the identity that such a diagnosis may confer. Further, patients and relatives’ interpretation of the meaning of social responses is likely to vary depending on what condition they see in themselves as eliciting such responses. Also, patients and relatives’ knowledge of the diagnosis probably ensured more homogeneity in the group of patients or relatives.

It was thought that the diagnosis of schizophrenia must have been known for a sufficiently long period of time by patients or relatives for them to have come across its repercussions, experienced the related social attitudes and formed their own views of schizophrenia. This was especially important as the survey aimed to measure, among other features, the stigmatisation directed at patients and perceived by patients and relatives. A duration of six months was considered to be probably adequate for patients or relatives to have had opportunity to come across possible stigmatising responses and develop their own responses.
Patients had to be in remission as it was considered that, despite an unreplicated report to the contrary (Link et al, 1997), a depressed or delusional mental state would interfere with objective perception of social and linguistic stigmatisation and bias the assessment of patients’ predisposition to enact stigmatisation. Persecutory delusions and hallucinations or depressive symptoms could exaggerate participants’ estimate of social stigmatisation (including rejection and discrimination) directed at them even though the contents of these symptoms is not always divorced from social stigmatisation. This means that the mental state even when affected by the symptoms of a mental disorder may resonate with objective social stigmatisation.

To get access to the target population of patients one option would have been to concentrate on in-patients immediately following their recovery and discharge. This would have reassured a relatively high response rate contrary to an alternative in which patients are traced in the community where some move several times over short periods of time and become practically untraceable. Yet, the first option would have meant focusing on a particular category of patients: those who had just experienced a major breakdown and been away from the community for some time, experiencing parallel yet probably somewhat different responses from staff and other patients in the interim. It was considered that this group of patients’ contribution to the survey was important but that, to have a more comprehensive picture, other patients living in the community with a diagnosis of schizophrenia needed to be included as well. To do so it was necessary to select the patients from a comprehensive list covering those living in the community as well as complementing the list with new admissions during the period of the survey.
4.2.3 The Sample

The list of all admissions with a diagnosis of schizophrenia, schizoaffective disorder, delusional disorder and other varieties of psychosis such as drug induced psychosis, acute and transient, and acute and polymorphic, admitted to St Lukes Woodside, University College and Whittington Hospitals in London was obtained in 1997 from the records held on Patient Administration System (PAS) of these hospitals accessed via the computer link of the Camden & Islington Community Services NHS Trust. Though admissions related to psychoses other than schizophrenia were not needed in the survey the composite list was more readily available from the PAS. In the interval from 1997 to 2000, the list was expanded by random inclusion of in-patient admissions with a diagnosis of schizophrenia.

The original list contained 2165 admissions. There were duplications of information as the list corresponded to admission episodes and some patients had more than one admission and/or had at times received more than one diagnosis. At a first stage, all episodes with a diagnosis other than schizophrenia were cancelled from the list. To select patients from the remaining list, a random number table was used.

There were three groups of patients. The first were patients who, by report of a carer, nurse, relative or doctor were in remission and knew their diagnosis for a period of more than six months. This group was approached for the survey as they were by definition part of the target patient population.
The second group were patients who, by report of a carer, psychiatric nurse, doctor or relative were ill, did not know the diagnosis or knew it for a period of less than six months. This group was not approached as they did not come under the definition of patients' target population. Arrangements were made instead to see these patients after their recovery. During the three year period of the survey such patients were approached for the survey only if they recovered and knew by then their diagnosis for more than six months. Patients who were mostly ill during the period of study, living in long stay wards and suffered from chronic severe schizophrenia were as such practically excluded from the study.

The third group were patients whose state of health and/or knowledge of their own diagnosis were not known as they had not been in contact with the services for some while, or did not have a key worker or relative who can give any information about their state or for whom it was not easy to locate or contact a relative or key worker. Among patients in this group who were traceable some satisfied the definition of the target population (were in remission and knew their diagnosis for more than six months). There were also patients who were practically untraceable. When no current key worker or social worker could be identified or when they did not know of patients' whereabouts and the latter were not contactable at their registered addresses, a reasonable degree of effort was made to locate them. This included returning to their registered addresses three times at different times of the day, evenings and weekends and if they were still not accessible asking the neighbours discretely about their whereabouts. If it was still not possible to locate them, efforts were made to trace them using data held in the directory enquiry and the Camden and Islington Health Authority family practitioners’ lists. This was quite rewarding as a number of patients could be located in this way and approached for the survey.
It was assumed that patients remaining untraceable after all the above measures would mostly correspond to those who are practically 'rootless' in the sense that they would not leave any trace of their whereabouts with their key workers, social services, psychiatrists or GPs and even with any relatives. It was considered that probably a large number of this group moved away as they experienced recurrences of their illness and developed hallucinations and delusions about their hostels, homes and neighbours so they would not have anyway satisfied one of the criteria for the target population of patients, i.e., being in remission, and their inaccessibility would not significantly affect the sample's representing the target population inasmuch as these patients were indeed those who would have been excluded from the survey as one of the survey's condition was for patients to be in remission.

One must acknowledge that the definition of the target population of patients would exclude those who are more or less permanently or very frequently ill and who might actually be exposed to higher degrees of stigmatisation. One must also consider the fact that those who were untraceable could have given the hospital fictitious names or addresses or moved out of their original addresses, not due to delusions about neighbours or spirits, but also or uniquely in relation to social stigmatisation. As such those defined as the target population might have, in actual fact, suffered lower degrees of stigmatisation than the whole population of patients with schizophrenia. This makes one think that the results of the study may in fact underestimate the actual level of social stigmatisation yet it is expected to be at least an indication of it. The target patient population was considered to be the only appropriate group whose views could represent the experience of patients with schizophrenia as neither those who were ill, incoherent or under the effect of delusions nor those who were untraceable could possibly contribute to the study.
4.2.4 **Procedure for the Conduct of the Survey**

A pilot trial was made by inviting patients and relatives with a letter to come forwards for the survey. This gave a very poor response rate of about 5 per cent. One option was to send the questionnaires themselves by mail but this was not done as it would have also led, as reported in the literature (Platt, 1985) to low response rates and data of poor reliability and validity. It was decided that patients, relatives and their carers should be approached in person. It is known that the presence of the interviewer would inhibit negative responses (McPherson & Cocks, 1983) reinforcing the effects of the social desirability (SD) factor. For this reason and others it was decided to include a social desirability scale into the attitudinal questionnaires (see below).

Patients and relatives were seen in various settings, for example, hospital wards after patients’ recovery, their homes, shelters, hostels and out-patient settings. Some relatives or patients who had moved to other countries such as Ireland or France or who lived in other parts of the United Kingdom and who could be traced were interviewed on the phone.

The purpose of the study was explained to patients and relatives. When service pressure allowed it and a carer could be identified, this was preferentially done in the presence or with the help of a nurse or other person familiar to patients and relatives. It was made clear that their decision to participate or not would not affect their medical care or social benefits in any way. Those patients and relatives who accepted to participate were requested to sign a consent form (Appendix I). When this was not possible, for example, in cases where the survey had to be conducted on the phone, their verbal consent was recorded on the consent sheet. In circumstances where patients
or relatives could not adequately read or write the questionnaire was read to them.

Patients were asked whether they knew their diagnosis and if yes whether they did so for more than six months. It was anticipated that at least some of the patients in the first group who were reported as ‘well’ by carers or relatives may turn out to be unwell at the time of the interview. This was also true for some patients in the third group who had not been in contact with the services for some time but could be traced. To check for any symptoms, a list of thirty six standard questions from SCAN (Schedule for Clinical Assessment in Neuropsychiatry) (Wing, 1992) was used with minor modifications (see Appendix V). The aim was to ask the same standard questions with the same wording to every patient and, to this end, one could have chosen standard questions from any alternative schedule and the choice of SCAN was arbitrary. The purpose of the assessment was not to confirm or disconfirm the diagnosis of schizophrenia but to make sure that the patient’s mental state was free from delusions, hallucinations, thought disorder and a depressive episode which could theoretically interfere with their perception of stigmatisation or predisposition to enact stigmatisation. It was not necessary to verify the diagnosis of schizophrenia as what was of significance was the fact that the patients had already been given a diagnosis of schizophrenia and had to face the related social stigmatisation over a sufficiently long period of time. The presence of a depressive episode was established using ICD-10 criteria, i.e., at least two of the following three symptoms: 1) low mood for at least two weeks, abnormal for the individual, most of the day, almost everyday, largely uninfluenced by circumstances, 2) loss of interest or enjoyment, 3) loss of energy or fatiguability. The condition on duration was disconsidered when there were evidence of severe depression with biological symptoms and/or suicidal ideation.
The SCAN questions were not necessarily asked of every single patient. For example, when patients showed objective evidence of thought disorder or spontaneous report of delusions before being asked the SCAN questions they were excluded from the survey until a later time when they would satisfy the criteria for entry.

All patients who were included in the study were those who did not show any objective sign of psychosis or depressive illness and whose responses to the SCAN questions were indicative of absence of psychotic symptoms and a depressive episode. The list included questions such as the probe for hallucination: “We ask this question of everyone and would like to ask you. Do you seem today or very recently to hear noises or voices when there is nobody about and no ordinary explanations seems possible, or see or feel things other people cannot? What is that like?” Also, verification for hallucinations: “Do you hear them in your head, or in your ears, or as though from outside? Where do they seem to come from?.” And insight into the hallucination: “How do you explain the voices? Where do they come from? Why do you hear them?” As the objective was not to prove the diagnosis of schizophrenia but to ascertain the absence of symptoms, the SCAN questions for example on whether the voices were second or third person or the length of the utterances were excluded from the list of questions asked. Similar considerations were given to questions on other hallucinations, thought disorder, delusions and depressive symptoms.

For each respondent age, gender, marital status, place of birth, ethnic origin, first language, occupation and the number of years of education were recorded before administering the questionnaires.
4.2.5 Perception of Stigmatisation and Tendency to Enact

Stigmatisation

A search of literature by Medline showed that there were instruments assessing perceived stigmatisation and the predisposition to enact stigmatisation but none contained the essential social desirability scale as described above. Rarely had any authors such as Angermeyer et al (1987) administered an SD scale such as Crowne-Marlowe inventory (1960) with the main questionnaire.

Most previous stigma questionnaires such as the Custodial Mental Illness Ideology Scale (CMI) by Gilbert and Levinson (1956) were designed to assess the ideologies of mental health workers and contained items which showed a high correlation with the F scale which assesses authoritarian personalities (Adorno et al, 1950). A high score on CMI represented an authoritarian modal personality among mental health workers (facilitated by selective recruitment, turnover and personality change in the work context) and suggested coercive handling of patients in congruence with custodial ideologies of the mental health system policies. Around the same time, Cumming & Cumming (1957) deployed a scale originally developed by Neil Agnew from the Department of Health, Saskatchewan, Canada. This proved to result into two scales: a social distance scale and a responsibility scale but no scale measuring authoritarianism.

Cohen & Struening (1962) used some items from CMI and F Scale in a new scale called Opinion about Mental Illness (OMI) and after a factor analysis they followed on Gilbert and Levinson (1956) and considered ‘authoritarianism’ to be a factor of stigmatisation. This tradition trailed on
into the work of Taylor & Dear (1981) who developed another scale, CAMI (Community Attitudes to Mental Illness) scale, using the OMI and another scale: CMHI (Community Mental Health Ideology) (Baker & Schulberg, 1967). Though they set out to develop an instrument to measure community rather than professional attitudes they were still tempted to follow the precedent and refer to one of the factors derived in their factor analysis as “authoritarianism”. Surely one could stigmatise without being necessarily authoritarian. Further, this sort of nomenclature would not assist in delineating the core components of stigmatisation. Brockington (1993) as well as Wolff et al (1996 a) who used CAMI in their community studies also adopted the idea and called one of the factors “authoritarianism” without any criticism or questions.

My study shows that what the previous authors recognised as ‘authoritarianism’ originally in the attitude of mental hospital staff corresponds indeed to a stigmatisation factor that can be more appropriately designated as emotional exclusion which can be seen in patients, relatives and also probably in the general public without them being necessarily authoritarian. It is likely that mental health professionals who are authoritarian also emotionally exclude the patients consciously or unconsciously so there is to be some correlation between authoritarianism and emotional exclusion of patients but the first concept is misleading when trying to grasp the core components of stigmatisation.

There are further problems with the existing scales. For example OMI and CAMI have included items which measure ‘benevolence’ towards patients and accordingly in their factor analysis have driven a factor called “benevolence”. Though one can argue that a benevolent attitude can come to compensate for stigmatisation intended or already exercised, stigmatisation by definition does not include benevolence itself, the latter coming in to allay the guilt related to being a stigmatiser.
As a result, scales such as OMI and CAMI do not measure stigmatising attitudes per se but a mixture of at least two different attitudes one of which is not a component of stigmatisation. Indeed, there are suggestions in Taylor & Dear's (1981) work which support this proposition. For example, in their study the ‘benevolence’ factor has a weak predictive power in relation to intended opposition to mental health facilities in one’s area. The benevolence factor “suggests a transcendent sympathetic attitude towards the mentally ill, which conceals important attitudinal variations exposed” by the other factors (pp. 237-8). Also, the interpretation of some of the items regrouped under the term ‘benevolence’ in both OMI and CAMI is complex and contradictory. For example a positive response to the following proposition: “More tax money should be spent in the care and treatment of people with mental illness” may mean benevolence but also the participants’ fear of mental patients making the former promoting the idea that patients must be treated more effectively to reassure ‘safety and security’ for themselves.

It was considered that attempting to validate a new instrument with the help of another instrument taken as a validity criterion but containing conceptual controversies would be ‘validating’ the new instrument with an existing instrument one assumes to be less valid than the new instrument. It was as such difficult to compare the instrument with an already established external measure satisfying the theoretical assumptions. There was then no gold standard to use here as an absolute measure of truth.
4.2.6 Development of the Questionnaires

4.2.6.1 Assessment of perception of stigmatisation

A stigmatisation questionnaire was constructed for the purpose of the study. It was composed of three parts: Part I assessing perception of stigmatisation by participants, part II assessing predisposition to enact stigmatisation by participants including a social desirability scale and part III assessing linguistic stigmatisation. To reduce the effect of social desirability still further, instructions stressed that participants’ names were not required and that there were no right or wrong answers and that we were just interested in their opinion.

Littlewood (1998) analysed the content of 142 personal explanatory model questionnaires (Kleinman, 1980) given to patients and relatives in London, Birmingham and Trinidad, in addition to recording patients’ own ideas about ‘serious psychiatric illness’ and ‘stigmatisation’ derived from a weekly clinically applied anthropology group (Littlewood, 1990) and a user group as well as consulting medical and social workers from various ethnic backgrounds in the UK and other countries such as India, Spain, Sri Lanka and Trinidad. The result of this work was a 26 item inter-cultural stigmatisation questionnaire assessing predisposition to enact stigmatisation.

In this survey, it was decided to assess perception of stigmatisation and linguistic stigmatisation in addition to predisposition to enact stigmatisation so it was felt that each part of the questionnaire needed to be relatively brief and concise so that responding to the whole questionnaire will be acceptable to patients (and other participants).
The 26 items from Littlewood (1998) of which three had been derived from Cumming & Cumming (1957) were pooled with 26 other items including three from Cohen and Struening (1962) and one from Cumming & Cumming (1957). The rest of the 26 items came from patients’ accounts in groups to which I acted as therapist in four inner city hospitals in London and the accounts of relatives and social workers during community assessments I did in homes, hostels, prisons, police stations, streets, day centres and homeless shelters and from the ideas of patients and relatives with whom I worked in Birmingham, Tehran and Paris. The pool of 52 questions was then scrutinized by myself and the questions were simplified and rephrased so that they each contain a single idea expressed in clear language. Thirty two items were excluded on the grounds of redundancy, complexity or assessing factual knowledge rather than attitude. Five questions detecting social desirability (Table 4.2) were interspersed within the twenty remaining questions (Table 4.1). The questionnaire was field-tested on patients and relatives on hospital wards in inner London and minor changes were made in wording to make the language more clear and simple.

The 25 questions were preceded by a short vignette about a man who becomes ill: “This man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.” It was felt that including a vignette would give some context to the abstract medical diagnosis and engages patients and relatives in the process of responding to the questionnaire. Also, as Brockman et al (1979) concludes it is likely that vignettes allow respondents to react in a comparable manner to their actual behaviour.

The vignette portrayed the typical picture of someone who develops schizophrenia for the first time. It was nevertheless felt likely that altering gender and age or replacing the word
‘schizophrenic’ with another would elicit a different response. In order to reduce the possible effect of the linguistic presentation of the diagnosis the term ‘schizophrenic’ was randomly replaced by different versions of the term such as ‘person with schizophrenia’, ‘person having schizophrenia’ and ‘schizophrenia sufferer’. Questions throughout the questionnaires were designed such that to obtain a high score the respondent needed to answer *yes very much* to some questions and *no, not at all* to others. This was to minimise the influence on the test of response sets produced by yea sayers and nay sayers. A high score indicated a higher perception of stigmatisation towards the patient in the vignette or the tendency to enact stigmatisation towards him.

One must emphasise that the majority of questions in the questionnaires on perception of stigmatisation (and predisposition to enact stigmatisation) measure perception (or predisposition to enactment) of *unjustified discrimination* (in the form of action, thought or feeling) as a major component of stigmatisation.
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<tr>
<th>Question</th>
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<tr>
<td>Would most people be happy if he were to work together with them in their workplace?</td>
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<td>Would most people think he should stay in hospital for his whole life?</td>
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<td>Would most people think that he should take part in the making of important family decisions?</td>
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<td>Would most people be happy to eat food which he has cooked?</td>
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<td>Would most people think he is very likely to become physically violent?</td>
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<td>Do most people think one of the main causes of his condition is a lack of moral strength or will power?</td>
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<td>If social services open a day centre for people like him in their neighbourhood, would most people have any objection?</td>
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<td>Would most people be frightened if this man came to live next door to them?</td>
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<td>Would most people avoid talking to him if possible?</td>
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<td>Would most people be happy if he married their sister?</td>
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<td>Would most people think this man is a bad person?</td>
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<td>Would most people be happy if this person became the teacher of their children?</td>
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<td>Would most people think he will be able to return to a completely normal life?</td>
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<td>Would most people be happy to sit next to this man on a bus?</td>
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<td>Would most people be happy to work in the mental hospital he and other people with similar problems are treated?</td>
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<td>Do most people think he has developed his condition to avoid the difficult problems of everyday life?</td>
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<td>Do most people think he should be allowed to vote?</td>
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<td>Do most people think he has become a failure in his life?</td>
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<tr>
<td>If he is married, do most people think that, because of his condition, the law should allow his wife to divorce him without his consent?</td>
<td></td>
</tr>
<tr>
<td>Do most people think his condition is a punishment for bad deeds?</td>
<td></td>
</tr>
</tbody>
</table>

Table 4.1 The list of questions used in the survey to assess perception of stigmatisation. The same questions were also used to assess the tendency to enact stigmatisation by replacing ‘most people with ‘you’ in all the questions. The factor analysis of the results on 258 patients and relatives proved 65% (13) of these questions to have construct validity. These 13 questions make up the final version of the scale (see Appendix III, A & B).
4.2.6.2 Assessment of predisposition to enact stigmatisation

Part II assessing predisposition to enact stigmatisation by participants contained the same vignette and the twenty questions in Part I with the difference that the questions asked how the respondents themselves felt about or acted towards the man in the vignette. This was done by replacing the subject of the questions: 'most people' with 'you'. For example 'Would most people be happy to eat food which he has cooked?' was replaced by 'Would you be happy to eat food which he has cooked?'. In this way the second part of the questionnaire was constructed to assess predisposition in patients and relatives to enact stigmatisation towards patients.

4.2.6.3 Assessment of linguistic stigmatisation

Interactions between those recognised as bearing a stigma and other people crystallise in a society's linguistic formulations of stigmatisation which patients adopt or reject as designations for themselves. Patients and relatives' responses are likely to indicate the relationship they develop with their illness, and how this relates to their personal identity. In other words, patients' and relatives' adoption of a particular designation is likely to be linked with their view of themselves and their self-concept. Therefore, to elicit patients' and relatives' discourse about their identity one could explore their explanation for their preference for one out of a range of different diagnostic designations. It was assumed that markers for underlying factors such as their personal identity, attitudes, feelings and beliefs were likely to be embedded within this discourse.

The linguistic questionnaire contained ten questions. The first was an open question asking the
participants how they usually called people who have schizophrenia when they spoke about them.

The second asked the participants how they would like other people to call those who have schizophrenia if, by chance, they themselves developed schizophrenia (or if they had already developed it). These two questions were separated from each other by the attitudinal questionnaires so that the participants would not automatically respond to the second question in the same way as they did to the first.

The next two questions were the same as the first two with the difference that participants were given four choices: schizophrenic, person with schizophrenia, schizophrenia-sufferer, person having schizophrenia. Each of these questions were followed by asking the participants to write in a few lines why they preferred that particular designation in the question concerned. The objective in asking the latter questions was not to find out which designation was 'better' but beyond that: to find out about participants' anxieties, needs, feelings, beliefs, attitudes about illness and cure, explanatory models, self-image, notions of agency, their use of terms as discourse for compensatory purposes, their deconstruction of the concept of schizophrenia and defence mechanisms against stigmatisation.

The last four questions asked the participants to estimate any devaluing connotations in the four designations by locating their devaluing intensity on a Likert scale from not at all devaluing to very much devaluing. These questions were put at the end of the linguistic questionnaire and were distributed after the participants had responded to the first six questions and the other parts of the questionnaire in order not to induce the ideas of devaluation and affect participants' discourse in their responses to earlier questions.
4.2.6.4 Standardisation of the questionnaire

a) Reliability

Reliability is the degree to which a scale yields consistent scores when the attitude is measured a number of times (Shaw & Wright, 1967). It was felt that the test re-test method had several disadvantages including the fact that the respondent having been tested once might influence their responses on re-test in the sense that they may simply respond in the same way as in the first test resulting in falsely high reliability estimates. More than that, the responses to the first test would be more spontaneous and on re-test respondents have had time to think of what ‘should be’ the answer and as such the spontaneity of the test is lost and the respondent may adopt a different attitude on retesting without actually having it on this second occasion. Also, the effects of these two facts may be different for different respondents (Shaw & Wright, 1967). For all these reasons, the assessment of reliability was done by split-half method on thirty patients and thirty relatives, computing Spearman-Brown coefficients as a measure of the internal consistency (homogeneity) of the questionnaire (Spearman Brown = 0.8690 for part I, 0.8277 for part II, and 0.7973 for part III). Cronbach alpha is an alternative coefficient which shows how much the items measure the same thing and in a sense, ‘hang together’. It carries the split-half method to its logical conclusion and considers every item as a separate scale to compare with all other items (Alpha = 0.9901 for Part I; 0.8819 for Part II and 0.8314 for Part III). When computation was done on only the thirteen questions derived by factor analysis (see chapter VII), similar figures were obtained. All these results indicate a high degree of internal consistency and reliability of the questionnaire.
b) Validity

The items of the questionnaire were scrutinised for face validity and it was estimated that they seemed to ‘make sense’ on the surface as valid measures of stigmatisation. The content validity was examined by systematically scrutinising whether each item covered an aspect of stigmatisation and whether the set of all items covered all constitutive features of stigmatisation such as branding, rejection, distancing, devaluation and discrimination.

The theoretical framework for the present study is described in the chapter entitled “A Unitary Theory of Stigmatisation” stipulating the universality of the stigmatising attitudes and their high determinedness and manifestations in constitutional, genetic, psychological and economic domains. As such sociodemographic factors are expected to explain only a small proportion of the variability in the tendency to enact or perceive stigmatisation. As this proved to be the case from the analysis of the results (see the chapter on results) and also was compatible with the results reported previously (Nuehring, 1979, Taylor & Dear, 1981) it supports the construct validity of the instruments of this study. Also, it was expected that the questionnaire if having construct validity would distinguish between the group of patients and the group of relatives in as much as patients compared with relatives are qualitatively different targets of stigmatisation as well as being its primary targets. Only a rough distinction between the scores of the two groups were expected as too much distinction might make one question the validity of the scale (Cronbach & Meehl, 1955) since members of the two groups are indeed expected to overlap as well because of the common aspects of their experience of stigmatisation. This was indeed the case. As will be seen in the chapter on results, patients and relatives had some significantly different stigmatisation scores. Also, as the above theory suggests that there would be high item
correlation, i.e., stigmatisers, pursuing self-interest, are likely to stigmatise more or less in several areas, the high internal consistency of responses to the questions is also another indicator of the construct validity of the questionnaire (Cronbach & Meehl, 1955). Overall, the pattern of these results provides support for the construct validity of the scales.

4.2.6.5 Choice of number of points on the Likert scale

Generally speaking a five-point Likert scale draws more data from respondents than a four point one. The higher gradation of responses makes assumptions about treating ordinal data as quantitative and the application to such ordinal data of t tests, factor analysis and linear regression (which have been originally designed for quantitative data) a more acceptable practice. Yet contrary to situations in which one assesses more neutral issues, such as people’s liking of a TV programme or preference for certain product, five- (or a higher number) point Likerts are not necessarily suitable when assessing patients on sensitive matters such as stigmatising attitudes because:

1) it would reduce patients and relatives’ cooperation and so the chance of completing the questionnaire by making it more lengthy and the task of responding to the questions more difficult, and

2) opting for a five-point scale means including a midpoint option such as “I have no particular view on this issue” which acts as a convenient means of avoiding self-revelation. In addition, experiments have shown that people tend to choose the middle point more frequently especially
when they have not thought enough about the subject (Rodeghier, 1996). In these experiments despite participants’ over-selecting the midpoint response, the relative ranking of the categories is generally the same as when the midpoint did not exist. Yet, this is not likely to be true when the questionnaire touches sensitive issues inasmuch as including a neutral midpoint ‘neither agree nor disagree’ in the Likert Scale functions as an easy option for people faced with rather probing questions on a quite private, personal attitude. They are then likely to prefer to take up a neutral stance rather than reveal their more nuanced attitude.

Considering the above reasons a four-point Likert was preferred with precaution in the interpretation of the statistical tests designed originally for quantitative data.

4.2.6.6 The social desirability scale

Reviewing existing instruments for assessing social stigmatisation it was found that though there were quite a few instruments for assessing stigmatising attitudes, the existing questionnaires did not, in general, attend to the significant issue of social desirability factor (see the chapter entitled “Routes to De-stigmatisation”).

Social desirability factor, which is defined as participants’ tendency to give ‘desirable’ answers in response to attitudinal questionnaires in order to put forward a more socially acceptable self-image is likely to take on pivotal importance when the questions probe sensitive areas of private feelings and behaviour related to discrimination and stigmatisation. Respondents may answer in a socially desirable way because, for example, there is no flesh-and-blood psychiatric patient
asking, for example, to rent a room in their homes. This tendency in pencil-and-paper surveys is likely to be a defence to present oneself as a ‘good’, ‘fair’ and ‘impartial’ citizen against the ‘threat made by questions’ or to comply with the experimenter by responding in such a way as to confirm the hypothesis tested.

There are at least two sets of data which support that people tend to respond in a socially desirable manner when asked questions about their attitudes towards patients with mental illness. The first is the fact that those variables that generally predict higher tolerance and positive attitudes such as higher social class, higher education and occupational status and income also typify communities that, in effect, resist the establishment of mental health facilities in their neighbourhoods (Segal et al, 1980). Also, participants interviewed about their attitudes towards a mental patient’s ‘need to find a place to live’ were significantly less willing to take part in a similar interview in future (compared with participants interviewed about a medical patient’s similar need) even if they asserted that they would welcome such patients. This means that people may indeed find it disagreeable to think about a mental patient moving into their neighbourhood (Farina, 1998, p. 252) even when they verbally respond that they would be tolerant. Though neither Segal nor Farina have looked at the above from a social desirability point of view, their findings support the idea that people tend to resort to social desirability in their responses to sensitive questions.

It was felt that what the existing questionnaires measured was likely to be distorted by the social desirability factor. This means that the corruptive effect of this factor is likely to affect the validity of these questionnaires in that what is being measured is not strictly speaking stigmatisation but a mixture adulterated with attempts to present ‘desirable’ feelings and actions in order to ‘satisfy’
the research team. Thus the inclusion of a social desirability scale in a questionnaire scrutinizing personal feelings was deemed necessary to ensure that what is being measured by the questions is nearer to what is supposed to be measured.

A preliminary scale was built composed of five questions (Table 4.2). Each question has two possible answers: Yes or No and only one of them was considered to be a socially desirable. For example, in response to the question: *Do you always practise what you would preach to this person or anyone else?*, ‘Yes’ is supposed here to be a socially desirable answer and gets a score of 1 while ‘No’ is not a socially desirable answer and gets a score of 0.

The split-half reliability coefficient (Spearman rho) for the items 1 to 4 of the social desirability scale for all participants was about 0.57 which is moderate in magnitude yet acceptable for practical purposes. The aim in this survey was to include a brief measure of social desirability for the length of the questionnaire to be practically acceptable to patients and relatives and, at the same time, practically allow to screen out of the computations those with uncomfortably high social desirability scores.

The same procedures regarding face and content validity as described above were applied to the social desirability items which were integrated in Part II of the questionnaire. The assumption underlying the construction of a social desirability scale is that those participants who get a high score on the scale are expected to get a lower score on a questionnaire which measures an undesirable trait such as predisposition to enact stigmatisation. A measure of the construct validity of the social desirability scale would then be to examine if there is a negative correlation between the social desirability score and the score on enacted stigmatisation. A priori one would
expect a moderate negative correlation as the social desirability factor is not the only factor
determining the response of the participants to the questionnaire on enacted stigmatisation. There
was indeed a moderate and significant, negative correlation (Spearman rho) of -0.372 at 0.01 level
between the two scores of the group of thirty patients and thirty relatives which is an indication
of the construct validity of the social desirability scale. This means that those who tended to get
higher scores on the social desirability scale also presented themselves in a way as to get lower
scores on their enacted stigmatisation.

A subsequent cross-validation of the social desirability scale proved the validity of the majority
of the questions. The scale was cross-validated on 31 female and 30 male undergraduate students
by conducting an experiment in which they were asked to answer the above questions from the
point of view of someone who would answer in a socially desirable way. The aim, they were told,
was to find out what people generally judge as a socially desirable answer to questions.

Previous research has shown that gender acts as a variable in at least some social desirability items
in the sense that a given item might not be discriminative of one or the other gender’s tendency
towards social desirability (Goldfried & McKenzie, 1962) so it was necessary to consider this
variable in the cross-validation.
1. Would you smile at this man and other people every time you meet them?

2. Do you always practise what you would preach to this person or anyone else?

3. If you say to this person or other people that you will do something, do you keep your promise no matter how inconvenient it might be?

4. Would you ever lie to this man and or other people?

5. Would you laugh at a dirty joke this man or other people may make?

Table 4.2  The preliminary list of questions assessing the social desirability factor. The first four of these questions proved to be valid in both genders on cross-validation and constitutes the final version of the scale interspersed in the questionnaire assessing the tendency to enact stigmatisation (see Appendix III, B).

The participants were given the above questions and the vignette quoted above and were asked to answer the questions not from their own point of view but from the point of view of someone who has decided to give responses that are most socially desirable. In other words, they were asked to decide, for each item, which responses people would give if they wished their replies to be seen as socially desirable rather than undesirable.

As such, one would expect a significantly higher number of participants to respond in the scored (socially desirable) direction for each item if what that item really measured were social desirability. This was actually the case for the first four items, i.e., they actually measured social desirability (p < 0.0005). The only exception was question number five (p = 0.249, NS) (Table 4.3).
Table 4.3 Differences between the proportions of the participants recognising as socially desirable, the scored versus unscored responses to the questions on the SD scale. For questions 1 to 4 there is a significantly higher number of participants responding in the scored direction as such confirming that the corresponding item measured social desirability. Chi Square Test.

Also, there were no significant differences between proportions of male and female students’ responses in socially desirable versus socially undesirable direction, i.e., all these questions were suitable for testing social desirability equally well in both genders except for the fifth question (p < 0.02). (Table 4.4).
Table 4.4 Differences between male (n = 30) and female (n = 31) undergraduate students in their recognising as socially desirable, scored versus unscored responses to the questions on the SD scale. There is no inter-gender differences for the majority of the questions on the scale.

Cross-tabulation. Fisher's Exact Test; two-sided.

It was interesting to notice that the fifth question was a good measure of social desirability in the male students (p < 0.01). Most these participants said they would consider ‘Yes’ to be the socially desirable response to the question 5 as one is supposed to laugh at such a joke in order to save the face of the person who has tried telling it. But this was not the case for females (p < 0.369) who did not show a significant preference in either direction. Presumably, for some female participants the socially desirable response was like that of the majority of males, and for other females the opposite: the socially desirable behaviour would be not to laugh at a dirty joke. This may indicate that cultural norms that delimit the behaviour of women are at times different from those guiding the behaviour of men (Goldfried & McKenzie, 1962).

In brief, the first four questions on the SD scale were valid and did not show any gender specificity. To make the scale inconspicuous it was integrated into questionnaire assessing
predisposition to enact stigmatisation. The significance of social desirability factor became more evident when during the factor analysis (see chapter on results) in that retaining those participants with high social desirability scores in the computation disrupted derivation of factors regarding enacted stigmatisation.

4.2.7 Statistical Tests

Analysis was carried out using SPSS (Norusis, 1988). Analysis of differences in counts was done using Chi Square test (Fisher's Exact test for a two-by-two table). Mann Whitney, Kruskal Wallis and Friedman tests were used for comparing ordinal data. To compare means of a variable for two groups t test was used. The use of independent sample t tests implies equality of variance for both groups. To adjust for any possible unequal variances a Levene test was performed. Factor analysis and varimax rotation were used to reduce the data to their essentials and extract factors underlying stigmatisation and calculate their scores for Part I (perception of social stigmatisation) and Part II (predisposition to enact stigmatisation) of the questionnaire. Linear regression was used to determine which independent variable(s) (sociodemographic factors) within a given model can predict the value of the dependent variables (stigmatisation score) derived by factor analysis. Reliability analysis was done by the split-half method and the Cronbach Alpha as measures of internal consistency of the questionnaires and the latter also for the analysis of the reliability of items of each factor extracted by factor analysis.

As mentioned above, though t tests, factor analysis and linear regression are devised to assess quantitative data, they are commonly applied to Likert scales with the understanding that they are
approximations as there is no reason to believe that the distance between one point of the Likert
scale and the next is necessarily the same as the one between that point and the one before.
Though some distortion may be done to the data, this practice done with caution is reasonably
safe especially for Likert scales with a higher number of scale points (Rodeghier, 1996).
CHAPTER V

SOCIODEMOGRAPHIC DATA AND QUANTITATIVE RESULTS OF THE LINGUISTIC QUESTIONNAIRE
5.1 Sociodemographic Data

5.1.1 Introduction

During the data gathering over two hundred and fifty hours were spent with patients and relatives in the field and, in addition to the quantitative questionnaires, more than one hundred and seventy-five pages of field notes and quotations of patients and relatives' discourse were amassed containing descriptions by participants of their thoughts and feelings.

After excluding patients who were reported as ill by their carer or proved untraceable following considerable efforts to locate them, 70.8% (107 out of 151) of the patients approached (those who were reportedly well and those whose state of health was not known but could finally be located and interviewed) consented to participate and satisfied the conditions of being in remission and knowing their diagnosis for a period of more than six months. Some patients did not have any relatives. Of the relatives of patients (whether ill, well or untraceable) who had a relative, 84% (151 out of 182 relatives) consented to participate and knew the diagnosis for a period of more than six months. As such, 258 (107 patients and 151 relatives) participated in the study (41.5% patients and 58.5% relatives). Seventy-five of the relatives were relatives of seventy-five of the participating patients. The age of the participants ranged between 19 and 85 with a median of 45. Forty-two were 15 to 29 years old, 82 between 30 and 44 years old, 82 between 45 and 59 years old and 51 people, 60 years old or above. One hundred and thirty-four (52%) of the participants were male and 124 (48%) female. One hundred and seven were single, 86 married or cohabiting and 65 separated, widowed or divorced. Participants had between 2 and 23 years
of education with a median of 12 years.

The majority, 173 people, were white (mainly British), 26 African, 39 African-Caribbean, 16 Asian mainly Middle Eastern or from the Indian Subcontinent, 3 of mixed and 1 of unknown origin. Two hundred and four participants were born in Europe, 16 in Africa, 22 in the West Indies, 13 in Asia and 3 in other parts of the world. The first language of the majority (209 people, 81%) was English. Twenty-one participants (8%) had another European language as their first language and 28 (11%) a non-European language as their first language.

Fifty-nine relatives (about 40%) were from social classes I & II, ninety (60%) from social classes III to V. One relative had never worked. The social class of one relative was unknown. There was no patient from social class I. Six patients (about 6%) were from class II, forty-seven (44%) from classes III to V. Forty-one patients (38%) declared themselves as ‘unemployed’ and thirteen (12%) were students. Patients in the ‘unemployed’ group had in general either never had the opportunity to work or had deteriorated since their last ever employment to a degree that the last employment could not be reasonably taken as an accurate representation of their present social class. The students were mainly in further education or university courses that they attended usually irregularly or intermittently due to recurrences of their illness. It seemed appropriate to consider these students in a separate category rather than assimilating them with the social class that graduates from such courses usually achieve. This, of course, should not be taken as a general feature of patients with experience of schizophrenia as there are surely those who finish their studies successfully, and there were quite a number of them in this study, yet this was not the general picture and there were patients who had started further education or university studies and had never completed their studies.
5.1.2 Social Class Differences between Patients and Relatives

There was a significant difference between patients and relatives; with a higher number of relatives from social classes I & II and patients from social classes III to V (Fisher’s Exact Test. P < 0.0005; Table 5.1). Patients who were unemployed or students were not included in the data as, for reasons mentioned above, it was considered appropriate not to assimilate them with conventional social classes. This was later on proved rewarding in relation to the discovery of a lower perception, by the ‘unemployed’ group of patients, of allocation of agency to patients in society, lower perception of linguistic stigmatisation (labelling) by the same group of patients, and lower emotional exclusion of patients by the students in the sample (see below).

![Table 5.1 The differences in social class composition between patients and relatives. There was a higher proportion of people from social classes III to V in patients compared with relatives. Fisher’s Exact Test, P < 0.0005.](image)

5.1.3 Distribution of Participants on the Social Desirability Scale

As described in chapter IV, the social desirability scale corresponded to responses to five questions incorporated into the attitudinal questionnaire and its score ranged from 0 to 5
depending on the frequency of participants’ attempts to portray a desirable social self-image. The cross-validation of the scale with 61 undergraduate students was done following the stigmatisation survey. In the cross-validation four of the five questions turned out to be valid. Yet, the scale practically distinguished almost the same group of people as having a high social desirability score whether only the four or all the five questions were used for eliminating from the computations, those patients and relatives who had a high tendency to give socially desirable responses. About 18% of the participants had a score of zero on social desirability, i.e., they did not show any tendency to lie in order to portray a desirable social image of themselves. About two thirds scored between 1 and 3 on the scale. About 15% had the highest scores of 4 or 5. Linear regression revealed that older age (50 plus) (Beta = 0.199, P = 0.003) and being divorced (Beta = 0.135, P = 0.046) were associated with higher SD scores. These two variables taken together explained only about 7% of the total variability of the SD scores and should not be given disproportionate weight (Multiple $R^2 = 0.066; DF = 2; F = 7.741; P < 0.001$). Further, it is to be noted that the relationship between being older or being divorced and higher SD scores are likely to correspond to pure associations rather than causal relationships.

Those participants with the highest range of scores, 4 to 5, located on the extreme percentiles of social desirability scores (above 85 centile) were excluded from all computations unless stated otherwise in the text. This led to 38 participants being removed from the list of participants, reducing the total number from 258 to 220.
5.2 Acceptance of the Diagnosis

5.2.1 Differences between Patients and Relatives in the Rate of Acceptance of the Diagnosis of Schizophrenia

Based on clinical observation it was expected that patients would be more likely than relatives to reject their diagnosis. Patients and relatives were asked whether they had accepted the diagnosis of schizophrenia on a scale 'rejected, unsure, accepted'. There were differences in percentage of patients on one hand and relatives on the other who had accepted, were unsure about or had rejected the diagnosis (Table 5.2).

<table>
<thead>
<tr>
<th>Have you accepted the diagnosis of schizophrenia? (Scale: Rejected, Unsure, Accepted).</th>
<th>Accepted</th>
<th>Rejected</th>
<th>Unsure</th>
<th>Sum of Rejected or Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient n = 92</td>
<td>59.8</td>
<td>28.2</td>
<td>12</td>
<td>40.2</td>
</tr>
<tr>
<td>Relatives n = 128</td>
<td>71.1</td>
<td>13.3</td>
<td>15.6</td>
<td>28.9</td>
</tr>
</tbody>
</table>

Table 5.2 Differences of proportions of patients and relatives who had rejected, were not sure about or had accepted the diagnosis of schizophrenia. Forty per cent of patients as opposed to 29% of relatives were either unsure about or had rejected the diagnosis.

A Mann Whitney test showed that the mean rank of acceptance of the diagnosis for patients was lower than for relatives which confirmed that patients showed a significantly lower degree of acceptance of the diagnosis than relatives (Table 5.3).
Table 5.3 The difference between patients and relatives in their degree of acceptance of the diagnosis of schizophrenia. Patients were significantly more reluctant than relatives to accept the diagnosis of schizophrenia.

a. A lower mean rank corresponds to a lower degree of acceptance of the diagnosis. (Scale: Rejected, Unsure, Accepted).

These results are not surprising as it is mostly patients who are the first targets of stigmatisation. It is likely that ambivalence and denial are used by patients and, to a lower extent, by relatives as defence mechanisms against stigmatisation. On this basis, it was hypothesised that patients would be relatively more reluctant to refer to themselves by designations which have connotations of illness and chronicity.

5.2.2 Ethnicity and Acceptance of the Diagnosis of Schizophrenia

It was considered that people already subjected to racial stigmatisation were going to be more likely to reject yet another source of stigmatisation, i.e., that of mental illness. African-Caribbeans would be likely to be reluctant to accept a diagnosis of schizophrenia as it would increase the burden of stigmatisation they are already facing in relation to their ethnicity and socioeconomic
position in the UK. On the contrary, Europeans in general would not be under any such prior stigmatising burden and would be understandably more likely to accept the diagnosis.

When different ethnic groups (Europeans, African-Caribbeans, Africans and Asians) among relatives were compared on their degree of acceptance of the diagnosis of schizophrenia it was revealed that there was a significant difference among relatives in their acceptance of the diagnosis depending on their ethnicity (Table 5.4) with African-Caribbeans having the lowest rate of acceptance of the diagnosis and Europeans the highest.

<table>
<thead>
<tr>
<th>Relatives' Degree of Acceptance of the Diagnosis and Their Ethnicity</th>
<th>N</th>
<th>Mean Rank*</th>
<th>Kruskal Wallis Test Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>European</td>
<td>90</td>
<td>68.02</td>
<td></td>
</tr>
<tr>
<td>African-Caribbean</td>
<td>21</td>
<td><strong>48.40</strong></td>
<td>Chi Square = 8.073;</td>
</tr>
<tr>
<td>African</td>
<td>8</td>
<td>57.25</td>
<td>DF = 3;</td>
</tr>
<tr>
<td>Asian</td>
<td>8</td>
<td>66.44</td>
<td>P &lt; 0.05</td>
</tr>
<tr>
<td>Total</td>
<td>127</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5.4 Relatives' acceptance of the diagnosis of schizophrenia based on their ethnicity. Kruskal Wallis test. (Scale 1 to 3: rejected, not sure, accepted). There is a significant difference among relatives of different ethnicities in their acceptance of the diagnosis of schizophrenia in a member of their family.

a. A lower mean rank corresponds to a lower degree of acceptance of the diagnosis of schizophrenia.

One should notice the relatively low number of Asians and Africans yet this would not exclude comparison between African-Caribbeans and Europeans by a Mann Whitney Test based on the original hypothesis (Table 5.5).
Table 5.5  African-Caribbean v. European relatives' acceptance of the diagnosis of schizophrenia. (Scale 1 to 3: rejected, not sure, accepted). African-Caribbean relatives are significantly less likely to accept the diagnosis of schizophrenia in a member of their family.

a. A lower mean rank corresponds to a lower degree of acceptance of the diagnosis of schizophrenia.

As mentioned previously, in the Caribbeans schizophrenia is not designated as such. It is called ‘madness’ and often considered to be a supernatural phenomenon (Littlewood, 1988). An African-Caribbean family in the West may feel confused and stigmatised and be unwilling to agree with a doctor who, using the Western classification systems, tells them that their relative is ill and has ‘schizophrenia’, resulting in lack of cooperation with and distrust in psychiatric facilities, prolongation of the illness and a consequent poorer prognosis for patients (Kiev, 1961).

Similarly, there were significant differences among relatives in their acceptance of the diagnosis based on their place of birth (Table 5.6). As shown in the table those relatives born in the West Indies were more reluctant than those born in Europe to accept the diagnosis of schizophrenia.
Table 5.6. The relatives' acceptance of the diagnosis of schizophrenia for the patient based on the former's place of birth.

a. A lower mean rank corresponds to a lower degree of acceptance of the diagnosis of schizophrenia.

There was no significant relationship between patients' ethnicity or place of birth and the acceptance or rejection of the diagnosis by the patients.

5.2.3 **Level of Education and Acceptance of the Diagnosis of Schizophrenia**

Those relatives who were unsure about the diagnosis tended to be more educated than both relatives who had categorically accepted or rejected the diagnosis (Table 5.7). This may reflect the fact that more educated relatives are more aware of the uncertainty of psychiatry itself about the validity of the diagnosis of schizophrenia and whether it is a spectrum of different conditions brought under the same term or whether it corresponds to a unitary condition (Table 5.7).
Table 5.7 The relationship between the relatives' level of education and their acceptance of the diagnosis of schizophrenia in a member of the family. Those relatives who were unsure about the diagnosis tended to be more educated. Kruskal Wallis test.

a. A higher mean Rank corresponds to a higher point on the scale of years of education (1 to 4)

There was no significant relationship between patients' level of education and the level of acceptance of the diagnosis by patients.

5.3 Assessment of Linguistic Stigmatisation

5.3.1 Quantitative Results

5.3.1.1 How would you refer to someone who has developed schizophrenia?

Fig. 5.1 shows the differences in proportions of preference for different designations — *schizophrenic, person with schizophrenia, schizophrenia-sufferer, person having schizophrenia*
by patients.

If these terms had meant the same to the patients, one would have expected almost equal groups of patients (roughly 25% of the total in each case) preferring each of these terms. This does not seem to be the case. The highest percentage of patients (about 41%) preferred the term *schizophrenia sufferer* for patients (Chi Square = 21.478 DF = 3; P <0.0005).

![Fig. 5.1 Patients choice of a designation for people who have experienced schizophrenia. Chi Square Test, P<0.0005. N=92](image)

In a similar way to patients, there were differences between proportions of preference for different designations in the population of relatives (Fig. 5.2). The highest percentage of relatives (57%) preferred the term *schizophrenia sufferer* for patients (Chi Square = 71.688 DF = 3; P <0.0005).
5.3.1.2 How would you like to be called if you developed (or have already developed) schizophrenia?

In the linguistic questionnaire, patients and relatives were asked how they would like to be called if they developed or had already developed schizophrenia. Fig. 5.3 shows differences in proportions of preference by patients for different designations for themselves. The diagram is very similar to the one in Fig. 5.1. The highest percentage of patients (40%) preferred the term *schizophrenia sufferers* for themselves (Chi Square = 13.565; DF = 3; P <0.004).
The same questions were asked of the relatives and as is portrayed in the bar diagram, Fig. 5.4, the highest percentage of relatives (55%) preferred the term schizophrenia sufferer for themselves. (Chi Square = 64.188; DF = 3; P < 0.0005).
5.3.1.3 The relationship between devaluation perceived in a designation and choice of that designation

Following the hypothesis that at least one of the reasons for any differential preference for some designations among patients or relatives could be the devaluing or stigmatising nature of those terms as opposed to others, patients and relatives were asked at the end of the questionnaire to score how devaluing each of the above designations was (on a four-point scale from very much devaluing to not at all devaluing). On factor extraction, these questions were revealed to load highly (0.752 to 0.883) in a single factor. The score for perception of linguistic stigmatisation was obtained by summing up the scores of the relevant questions assessing devaluation perceived in the four designations. Devaluation was considered to be associated with rejection and distancing and this total score was called linguistic stigmatisation score. On the basis of this score, two groups of people were distinguished: those who did not perceive any stigmatising loading in language and those who perceived such a loading to a more or less degree.
Fig. 5.5 shows the contrast in size between the two groups. In the group who perceived stigmatising loading in language there was a gradation in the intensity of this perception. In this group (88% of the total), 22% perceived mild to moderate loading, 43% moderate to severe, and 23% quite severe loading (all percentages of the total of 220 participants). It is to be noted that even part of the 12% who claim they see no stigmatising loading in linguistic forms are doing so to reclaim value for patients and, as will be noted later, indeed they do see stigmatising loading in language (see below).

Table 5.8 shows a comparative assessment of the perception of devaluation in the four terms under question in patients and relatives separately. Friedman test is non-parametric and can compare several related samples to see if there is any significant difference between their ordinal scores. Related samples, in the case of patients for example, are the same group of patients responding to an identical question about devaluation in a different designation. The table indicates that both patients (Chi Square=114.465; DF=3; P < 0.0005) and relatives (Chi
Square=31.418; DF=3; P < 0.0005) showed a statistically significant difference in their perception of devaluing connotations in these terms.

<table>
<thead>
<tr>
<th>Devaluing Nature of Different Designations Perceived by Patients and Relatives</th>
<th>Devaluation Mean Rank*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Is it devaluing to call a person who has developed schizophrenia as</strong></td>
<td>Patients' response</td>
</tr>
<tr>
<td>n = 92</td>
<td>n =128</td>
</tr>
<tr>
<td>schizophrenia sufferer?</td>
<td>2.29</td>
</tr>
<tr>
<td>person with schizophrenia?</td>
<td>2.33</td>
</tr>
<tr>
<td>person having schizophrenia?</td>
<td>2.41</td>
</tr>
<tr>
<td>schizophrenic?</td>
<td>2.97</td>
</tr>
</tbody>
</table>

**Friedman Test**

Chi Square=31.418; DF=3; P < 0.0005

Chi Square=114.465; DF=3; P < 0.0005

Table 5.8 A comparison of the devaluing nature of different designations perceived by patients and relatives. In each group (patients or relatives) there is a statistically significant difference in the perception of devaluation between different designations. Patients and relatives perceive a gradient of devaluation, lowest in general in terms such as schizophrenia sufferer and highest in schizophrenic.

a. A higher mean rank corresponds to a higher perception of devaluation in the term concerned.

5.3.1.4 Comparison between patients and relatives in how they refer to themselves or to patients

It was hypothesised that patients would be relatively more reluctant to refer to themselves by designations which have connotations of illness and chronicity and could be perceived as devaluing (p. 195). An indication which prompted this hypothesis was the fact that a higher
percentage of patients (about 40%) rejected the diagnosis of schizophrenia or were ambivalent about it compared with only 29% of the relatives.

When all the counts of preference for all the designations were entered into a cross-tabulation for patients on the one hand and relatives on the other it was revealed that there was a significant difference between patients and relatives in their preferred designation for referring to themselves (Chi square = 8.427; DF = 3; P < 0.038). Also, there was a significant difference between patients and relatives in their preferred designation for referring to other patients (Chi Square = 9.825; DF = 3; P < 0.05).

As the bar diagram in Fig. 5.6. shows there was, in patients compared with relatives, less of a tendency to refer to themselves as *schizophrenia sufferer* and more of a tendency to refer to themselves as *schizophrenic*.
Table 5.9 shows a cross-tabulation of preference for the diagnostic designations for themselves by patients and relatives. It indicates that there is a statistically significant difference between patients and relatives in their preference for at least two of the designations (P < 0.05). High positive residuals in cross-tabulations are indicative of where any significant difference between the groups come from. Looking at the residuals it is clear that the essential difference between patients and relatives is in their preference for *schizophrenia sufferer* as opposed to *schizophrenic* (residuals of about 7.1 to 8.2).

Another method is to calculate the significance for all the pair of terms. To do a post hoc test on specific items of a cross tabulation needs stricter criteria. The reason is that when one does, for example, twenty experiments on placebos the possibility of getting a significant result by chance is on average one out of twenty. In a single test at 0.05 level the possibility of getting a significant result which is wrong is 5 per cent so when one does a set of tests simultaneously the possibility of getting a significant result which is wrong is understandably more than 5 per cent (Cook & 207)
Farewell, 1996). To correct for this it is necessary to use stricter criteria in the battery of post hoc tests. One method which is called Bonferroni correction is to multiply any post hoc ‘significant’ result by the number of tests performed within the set.

In the above case, there is a possibility of six tests to compare six different couples of designations. The only couple which gave significant results, as far as difference between patients and relatives was concerned, was that of schizophrenia vs. schizophrenia sufferer (P < 0.007).

Comparing the proportions of patients and relatives who had preferred schizophrenia sufferer on one hand and those who had preferred schizophrenics on the other by cross-tabulation using Fisher’s Exact Test resulted in a statistically significant difference between them (P < 0.007) which even after Bonferroni correction remained below 0.05 (0.007 x 6 = 0.042) (Table 5.10).

<table>
<thead>
<tr>
<th>Participants' Preference for a Diagnosis for Themselves</th>
<th>Patients</th>
<th>Relatives</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia sufferer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Count</td>
<td>37</td>
<td>71</td>
<td>108</td>
</tr>
<tr>
<td>Expected Count</td>
<td>45.2</td>
<td>62.8</td>
<td></td>
</tr>
<tr>
<td>Residual</td>
<td>-8.2</td>
<td>8.2</td>
<td></td>
</tr>
<tr>
<td>Person having schizophrenia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Count</td>
<td>13</td>
<td>20</td>
<td>33</td>
</tr>
<tr>
<td>Expected Count</td>
<td>13.8</td>
<td>19.2</td>
<td></td>
</tr>
<tr>
<td>Residual</td>
<td>-0.8</td>
<td>0.8</td>
<td></td>
</tr>
<tr>
<td>Person with schizophrenia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Count</td>
<td>19</td>
<td>22</td>
<td>41</td>
</tr>
<tr>
<td>Expected Count</td>
<td>17.1</td>
<td>23.9</td>
<td></td>
</tr>
<tr>
<td>Residual</td>
<td>1.9</td>
<td>-1.9</td>
<td></td>
</tr>
<tr>
<td>Schizophrenic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Count</td>
<td>23</td>
<td>15</td>
<td>38</td>
</tr>
<tr>
<td>Expected Count</td>
<td>15.9</td>
<td>22.1</td>
<td></td>
</tr>
<tr>
<td>Residual</td>
<td>7.1</td>
<td>-7.1</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
<td>128</td>
<td>220</td>
</tr>
</tbody>
</table>

Table 5.9 A cross tabulation of patients and relatives’ preference for a term to refer to themselves if they developed or had already developed schizophrenia. Chi Square = 8.427; DF = 3; P < 0.05.
Table 5.10 A comparison of rates of preference by patients and relatives for *Schizophrenia Sufferer* and *Schizophrenics* as a designation for themselves. Fisher's Exact Test, $P < 0.007$ (2-sided). Bonferroni Correction: $0.007 \times 6 = 0.042$.

<table>
<thead>
<tr>
<th>Participants' Preference for a Diagnosis for Themselves</th>
<th>Patients</th>
<th>Relatives</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia Sufferer</td>
<td>37</td>
<td>71</td>
<td>108</td>
</tr>
<tr>
<td>Schizophrenic</td>
<td>23</td>
<td>15</td>
<td>38</td>
</tr>
<tr>
<td>Total</td>
<td>60</td>
<td>86</td>
<td>146</td>
</tr>
</tbody>
</table>

It is interesting to see possible reasons why patients' compared with relatives had a relatively lower tendency to refer to themselves as schizophrenia sufferer and a relatively higher tendency to refer to themselves as schizophrenic.

As mentioned above, it was hypothesised that there might be some difference between patients and relatives in their perception of devaluation attached to the term *schizophrenia sufferer* due to its connotation of illness and chronicity. A Mann Whitney test actually showed that there was a significant difference between patients and relatives regarding the devaluing connotations of *schizophrenia sufferer* in that patients, though on the whole keeping *schizophrenia sufferer* as their first choice, saw relatively more devaluing connotations in the term than their relatives (Table 5.11).
Is 'schizophrenia sufferer' devaluing as a diagnosis?

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Devaluing Ranks*</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>92</td>
<td>122.46</td>
<td>11266.50</td>
</tr>
<tr>
<td>Relatives</td>
<td>128</td>
<td>101.90</td>
<td>13043.50</td>
</tr>
</tbody>
</table>

Mann Whitney Statistics

Mann-Whitney U = 4787.500; Wilcoxon W = 13043.500; Z = -2.457; \( P = 0.014 \)

Table 5.11 A comparison of the perception of devaluation in the term schizophrenia sufferer by patients and relatives. The patients perceived relatively higher devaluing connotations in the term schizophrenia sufferer than relatives.

a. A higher mean devaluing rank corresponds to a higher devaluation perceived in the term schizophrenia sufferer.

The discourse of relatives and advocacy organisations consists of trying to get patients exonerated by emphasising the idea that they have an illness and are suffering. This preference for Schizophrenia-sufferer seems to come from the Christian tradition of regarding the sufferer as an object of care, concern and cure (Jackson, 1985). On the contrary, the discourse of patients tends in general to shy away from the notion of illness and suffering. This is in agreement with the fact that 40% of the patients (as opposed to 29% of the relatives) resisted accepting the diagnosis of schizophrenia. Another confirming evidence that some patients wished to avoid notions of 'illness' in their preferred designations and relatives did less so is the fact that 'person having schizophrenia' too was considered by patients as more devaluing than by relatives. This was not the case as far as person with schizophrenia was concerned (\( P = 0.111 \)) presumably because there are more suggestions of illness in 'having something than in 'being with' something. (Table 5.12).
Is 'person having schizophrenia' devaluing as a diagnosis?

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Devaluing Ranks</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>92</td>
<td>122.11</td>
<td>11234.00</td>
</tr>
<tr>
<td>Relatives</td>
<td>128</td>
<td>102.16</td>
<td>13076.00</td>
</tr>
</tbody>
</table>

*Mann Whitney Statistics*

Mann-Whitney U = 4820.000; Wilcoxon W = 13076.000; Z = -2.384; *P* = 0.017

Table 5.12 A comparison of the perception of devaluation in the term *person having schizophrenia* by patients and relatives. The patients perceived relatively higher devaluing connotations in the term *person having schizophrenia* than relatives.

a. A higher mean devaluing rank corresponds to a higher devaluation perceived in the term.

Why did the patients have a relatively higher tendency compared with relatives to prefer the term ‘schizophrenic’ to refer to themselves? One possibility might be that patients would consider *schizophrenic* as less devaluing than relatives so they use it more frequently than the latter. When patients and relatives were asked to score how devaluing ‘*schizophrenic*’ was (on a four-point scale from *very devaluing* to *not at all devaluing*) the majority (72%) identified some devaluing quality in the term schizophrenic with nearly half (46%) considering it as very much devaluing (Fig. 5.7).
A Mann Whitney test was done to verify whether the patients’ relatively higher preference for schizophrenic compared with the relatives was due to the patients’ perceiving schizophrenic as any less devaluing than relatives. There was no statistically significant difference between the devaluing connotation perceived by the patients in the term schizophrenic compared with the relatives (P = 0.863, NS) (Table 5.13).

<table>
<thead>
<tr>
<th>Is schizophrenic devaluing as a diagnosis?</th>
<th>N</th>
<th>Mean Devaluing Ranks</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>92</td>
<td>109.68</td>
<td>10090.50</td>
</tr>
<tr>
<td>Relatives</td>
<td>128</td>
<td>111.09</td>
<td>14219.50</td>
</tr>
<tr>
<td><strong>Mann Whitney Statistics</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mann-Whitney U</strong></td>
<td>5812.500</td>
<td></td>
<td>10090.500; Wilcoxon W = 10090.500; Z = -0.173; P = 0.863</td>
</tr>
</tbody>
</table>

Table 5.13 A comparison of patients and relatives in their response to the question ‘Is schizophrenic devaluing as a diagnosis?’ There is no significant difference between patients and relatives in their perception of devaluation in the term schizophrenic.

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Surely patients do not use this term relatively more frequently than relatives because they think it is any less devaluing. So why did the patients compared with the relatives tend to use this term more often to refer to themselves? Could it be that patients use the word *schizophrenic* relatively more frequently than relatives for claiming, solidarity and compensatory purposes? This impression was strongly confirmed by verbal accounts and testimonies of patients and relatives—their discourse—that will be discussed in detail later. Suffice it to say that though, in their verbal discourse, the majority of patients reported that the term *schizophrenic* suggested violence and danger, reclaiming by a subgroup of patients explains patients' excess percentage of preference for the term 'schizophrenic' compared with relatives.

In conclusion, patients in general, as intensely as relatives, believe that the term 'schizophrenic' is devaluing while a minority of patients prefer the term for revalorisation (reclaiming), solidarity with other patients, or compensatory (entitlement to support and benefits) purposes while relatives seem to have fewer reasons to consider 'schizophrenic' as a worthwhile designation for patients. This combination of a tendency to avoid identification with an 'ill' person on one hand—some patients' tendency to avoid the term *schizophrenia sufferer*—and patients' reclaiming and compensatory use of the term *schizophrenic* on the other seem to be responsible for the difference between patients and relatives in their preference for the term *schizophrenic* v. *schizophrenia sufferer*. It has to be emphasised that this is a minority tendency in patients and the majority of both patients and relatives still prefer the term *schizophrenia sufferer* over all other terms.
5.3.1.5 Experimental evidence of reclaiming

Patients’ perception of their exclusion from mutual transactions such as working in other people’s workplace, teaching other people’s children, marrying people’s close relatives or living in others’ close neighbourhood is subsumed in the scores of one of the factors extracted by factor analysis from patients’ responses to the part of the questionnaire assessing patients’ perception of stigmatisation (see chapter on factor analysis).

The ANOVA (analysis of variance) test is devised for dependent variables on a quantitative scale and the perception of transaction exclusion score in this experiment is derived by factor analysis from ordinal data with the assumption that the distance between points on the Likert scale of the questions are almost identical. An ANOVA test showed that there was a statistically significant difference (P< 0.05) between the means of the scores of *perceived transaction exclusion factor* for four groups of patients who perceived different levels of devaluation in the term *schizophrenic* (from ‘not at all devaluing’ to ‘very much devaluing’) (Table 5.14).
ANOVA

<table>
<thead>
<tr>
<th>Perceived Transaction Exclusion Score</th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Between Groups</td>
<td>11.022</td>
<td>3</td>
<td>3.674</td>
<td>3.157</td>
<td>0.029</td>
</tr>
<tr>
<td>Within Groups</td>
<td>102.427</td>
<td>88</td>
<td>1.164</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>113.450</td>
<td>91</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5.14  A comparison of the means of transaction exclusion scores for four group of patients who perceive different levels of devaluation in the term schizophrenic. There is a statistically significant difference between the means for the four group of patients.

The fact can be shown graphically in a plot of the means of perceived transaction exclusion scores as a function of the devaluation perceived in the term 'schizophrenic' (Fig. 5.8). It shows that the group of patients who declared the term 'schizophrenic' as 'not at all devaluing' had paradoxically relatively high scores on their perceived transaction exclusion of patients in society. By their relatively high scores they implied that society does not want to work with them, accept them as a neighbour or come into partnership with them, for the fact that they are diagnosed as 'schizophrenic'. And yet, as a reaction to this exclusion, rejection and devaluation, they reclaimed that 'schizophrenic' is not at all devaluing or indeed should not be so. The curve shows that those patients who say they perceive 'not much' devaluation in the term 'schizophrenic' have a similar tendency but to a more limited extent. These two groups actually report they perceive a level of social rejection and devaluation towards people with a diagnosis of schizophrenia which is disproportionate to their claim that 'schizophrenic' is not at all or not much devaluing. Such a phenomenon is absent when one considers the equivalent plot for the relatives though relatives
Is Schizophrenic Devaluing as a Diagnosis?

Fig. 5.8. Patients' perceived exclusion from transactions as a function of the devaluation they perceive in the term 'schizophrenic.' The perception of the stigmatisation is relatively low for the 'A little' group and increases for the 'Very much' group. The 'Not at all' group and, to a lower extent, the 'Not much' group seem to reclaim 'no devaluation' as a defence for the high stigmatisation they perceive. The ordinate shows z scores. N = 92

Is 'Patient Having Schizophrenia' Devaluing as a Diagnosis?

Fig. 5.9. Patients do not use all designations for reclaiming purposes. A comparison with fig. 5.8. shows that there is no sharp rise in perceived transaction exclusion for patients who consider the term as 'Not at all devaluing.' Instead, the perception of transaction exclusion increases in line with the perception of devaluation in language. The ordinate shows z scores. N = 92
do use the term schizophrenic for reclaiming purposes yet they do so to a much more limited extent.

Contrary to what is the case with the term ‘schizophrenic’, patients would not use terms such as ‘person having schizophrenia’ for reclaiming (Fig. 5.9). This is understandable considering patients’ tendency to avoid the notion of ‘having an illness’.

5.3.2 Discussion

If we consider that devaluation is one of the cores of stigmatisation, the devaluation perceived in language used to refer to patients has indeed to do with stigmatisation and it is this feature that is reflected in the proportion of preference for different designations displayed by the bar diagrams (Fig 5.1 to 5.4). A comparison of Fig. 5.1 to 5.4 and Table 5.8 shows that the frequency of preference for the terms vary in general mostly along with their devaluing connotations. The likely explanation is that people choose or avoid these designations guided by the devaluing connotation they perceive in them.

A minority of patients tend to avoid the term schizophrenia sufferer which is likely to be seen by them as objectifying the individual as having a career of suffering without referring to their personhood.

Perception of devaluing connotations is only one factor guiding the choice of linguistic designations and, as discussed above, other features such as reclaiming are likely to be involved.
This is why the frequency of preference for the word ‘schizophrenic’ in patients is not as low as could have been predicted on the sole basis of its measured devaluing connotations (Fig. 5.3, Table 5.8).

These results show that both patients and relatives have markedly significant preferences for how they wish to call a patient and how they wish to be called. The statistically significant differences between proportions of preference for various designations indicate that there is a meaningful tendency to discriminate between these terms and that there are significantly distinct points of views in patients and relatives about connotations, meanings and appropriateness of how one chooses to refer to patients. This indicates that language is not a neutral issue on which people adopt uniform positions. This difference in concern about meanings and connotations, about how one can summarise one’s identity or that of others in a few words, is likely to show some of the personal feelings and motivations of patients and relatives. That patients and relatives would not consider designations for schizophrenia as merely equivalent is demonstrative of:

a) an anxiety about the diagnosis of an illness such as schizophrenia, its significance and implications

b) their allegiance to a particular discourse, i.e. the ideological and political stance they associate with these terms

c) an implied political request for a reconsideration of personal attitudes towards patients.

The above results were based on simple counts and though they demonstrated general trends and
preferences they did not attend to the subtleties of patients and relatives’ responses and the ‘small prints’ of their testimonies. A more in-depth understanding of these feelings and motivations is likely to be achieved by exploring patients’ and relatives’ discourse.
CHAPTER VI

PATIENTS’ AND RELATIVES’ DISCOURSE
6.1 Patients’ and Relatives’ Discourse

6.1.1 Introduction

The following is an exploration of patients’ and relatives’ verbal discourse in their detailed responses to the two open questions (‘how they usually called people who had schizophrenia when they spoke about them’ and ‘how they would like other people to call those who have schizophrenia if, by chance, they [patients and relatives] themselves developed schizophrenia or if they had already developed it’) and the two other open questions on the reasons for their choices. In addition to representing feeling and reactions of these people to stigmatisation, the discourse expresses a much broader set of existential problems they face.

In the comments that follow any personal names have been changed to protect the identity of patients. Almost all comments whether positive or negative have been included either individually or by a prototypic quotation.

A number of patients and relatives sent letters expressing their experience of stigmatisation or asked for assistance. Some families asked for medical advice and especially information about the illness. Others requested for medical or social help for patients who were being approached and I made appropriate referrals for them to helping agencies.
6.1.2 Patients' Feelings about Having Schizophrenia

The patients commonly expressed their feelings about having schizophrenia by the medium of describing their feelings towards fellow patients and their condition: “When I talk to someone who has that mental illness sometimes I feel depressed. Maybe when he speaks to me I don’t really get him normally.” [sic]. They expressed indirectly their appreciation of their own situation when they get better: “but if he has improved... his speech... then I might say that is okay.” They also pointed out the feelings they have when other people talked about the illness: “When I hear ‘schizophrenic’ I get scared. [It] brings back memories of my illness.” “‘Schizophrenic’ makes me sad, sorry and unhappy about somebody who is ill.” Some patients preferred to refer to other patients in relation to the feelings that having the illness can cause: “Distressed”; “Isolated, misunderstood, misunderstanding” or “someone with diminished self-respect”, or “anxious and depressed.” “If you develop it you would be lonely and mad.”

Patients referred to other patients (and by implication, themselves) as “lonely people”, “unfortunate”, “unlucky” and “a little group of their own, separate from others, isolated.” The intensity of this isolation was at times such that patients had to ask other people to speak to them: “People sometimes do not speak to me...I tell them to talk to me....”

The acceptance of the diagnosis was sometimes followed by a commentary implying identification with and sensitivity to the feelings of other patients: “‘A schizophrenia sufferer’ knows all about his or her problems. [It] makes him feel sad.” “Depending on whether the person I am talking to would be ashamed by the word schizophrenic... I feel sorry for them.” This sensitivity was also
present in relation to other references to the illness or in efforts to avoid any references to it. One patient said: "[I speak about them] with concern and caution." "I don’t enquire about their diagnosis because they might feel embarrassed." "I speak with them very carefully because I don’t want to upset them. I understand their sickness and I would discuss [their problems] with them. If they feel troubled, I want to help them." This capacity to understand other patients was at times explicitly linked to one’s own experience of the illness: "I speak about them very sensitively. Before this illness, I had little understanding [about] people who suffer from mental illness.” Now “I understand their sickness” and “mental disability...It’s upsetting”; “[I’d say] sufferers [as] I don’t want them to feel neglected.” This was on occasion a reference to lack of patients’ agency. Schizophrenia “can be the result of anything [so] you cannot blame the person as responsible.” “I treat them with respect.”

This constellation of feelings in patients vis-à-vis other patients’ condition are indeed their own past or present feelings vis-à-vis their own condition and its consequences including stigmatisation: depression, anxiety, fear, trouble, upset, shame and embarrassment, isolation, rejection, alienation and a host of other feelings that even people who are not already affected with schizophrenia are likely to find difficult to withstand.

6.1.3 Emergence of Explanatory Models for Schizophrenia

The emergence of some explanatory or descriptive model for the illness or behaviour of patients was interestingly common in patients’ discourse. These explanatory and descriptive models were indeed indications of how they generalise their own personal experience of schizophrenia to the
group of patients with schizophrenia which could be an element underlying solidarity with other patients.

The idea of the difficulty in speaking well, a need to talk and a need for someone to listen was repeated quite frequently in patients’ discourse: “It [schizophrenia] means a person who is not likely to speak well and is talking in a different way. Someone whose mind or brain is not quite sure of what he is saying.” “[They are] angry, scared, frightened people who have something to say no one listens to because they think they are mental.” “People think we are mental. We’ve forgotten things we try to remember. We can’t remember them so we become ill.” And another patient: “[These are] people who have problems who cannot talk them out so they come to hospital to talk them out.”

Explanatory models included at times a summary of patient’s own history of illness: “Schizophrenics [are generally] unemployed. [It’s about] somebody who has been at work and something has happened. An argument about something.” Sometimes the description was an imagery of patients’ mental state when they are ill: “It’s like being in a dark cloud. You cannot see around it. It’s so misty and foggy. You think if somebody is laughing they are laughing at you.”

There were on occasions attempts to give a biological explanation for the illness: “It is the result of a chemical imbalance in the brain” or a psychological one: “a stress-related inability to react to a situation.” Sometimes the responses were vivid, shocking descriptions of patients’ personal history: “People who have been deeply wounded by childhood experiences and/or other experiences.” “[They are] kids who are abused by teachers. Kids who have been dropped on
their heads. Kids who have been chucked in the back of police cars.”

The relatives’ language sometimes was replete with medical words which suggested they had made efforts to read up medical books out of anxiety and in search of a better understanding of the illness: “also, often tachycardia is one of the earlier symptoms, [It’s] ‘balspharospasm’ related.” [sic]. Like that of patients, the relatives’ discourse sometimes revealed their explanatory model of the illness and stigmatisation: “They have had some sort of trauma which has changed their brain pattern.” “People do tell those who have schizophrenia so many things that they lose their confidence.”

Other instances of explanatory models for schizophrenia emerged throughout within patients and relatives’ discourse and will be reported in the following sections.

6.1.4 Revalorisation as a Defence against Stigmatisation

“‘Schizophrenic’ is an object not a human being. Someone who has lost the traits which are commonly considered as human,” said a patient. “A mad axeman; a poor little man who is homeless,” added another. “An alien being”, “a leper sort of thing”, “an ‘inhuman’ being” were the words of a relative. The ‘intensity’ of definition subsumed in schizophrenic was at times viewed to be of the same nature as the definition of someone’s gender: “‘Schizophrenic’ defines a person in the same way that ‘man’ or ‘woman’ does” said a patient. “There would be no detachment from the illness.”
The majority of patients disliked the word ‘schizophrenic’ and some believed that the prefix ‘schizo’ would overcome any linguistic structure into which it is inserted: “The bloody nasty word is still there.” They defined it in terms of the reaction it could elicit from society: “people are rude about them...Take the mickey [out of them].” It meant a long list of negative attributes: “unpredictable”, “abrupt”, “bold”, “scary”, “aggressive”, “unbalanced”, “cripale”, “bad”, “violent” “horrible, final, operative, serious, frightening”, “crazy”, “negative”, “terrible” “mad”, “incurable”, “not right”, “definite”, “angry, upset”, “not so happy”, “round the bend” and “liable to do anything.” Patients themselves were frightened of the discourse of ‘schizophrenic’: A ‘schizophrenic’ implied “a dangerous person one does not want to be with or speak to.” “I don’t know the exact meaning but that frightens me.”

It is not just how ‘schizophrenic’ defines the person which mattered but what sort of ‘tool’ it is.

“ ‘Schizophrenic’ is very general and too much bandied around.” It is “very clinical”, “not empathic”, “permanent like a curse”, “a label difficult to shake off”, “a harmful influence”, “a tag to identify people”, “the illness itself”, “like being called a name”, “harsh like an insult”, “devaluing”, “putting down”, “derogatory”, “heavy” and “alienating.” The efforts to describe ‘schizophrenic’ seemed to have exhausted the available vocabulary: it was “something more”, “a different level”, and had “no explanation.”

The relatives’ discourse shared some aspects with that of patients but also had specific features. One of the most striking features of the relatives’ discourse was how they felt when they heard the word: “It is like a knife in the heart when you hear it on TV.” One relative who was suffering from cancer said: “I’d rather have my cancer.”
In addition to some of the negative attributes mentioned above, 'schizophrenic' meant to relatives "a horror", "a plague", "a psychopath", "affected", "lunatic", "callous", "off his rocker", "totally changed", "killer and criminal", "strange and difficult", "possessed by evil", "out of control", "condemned for life" and "finished", "with no hope." It was "ominous", "categorical", "critical", "magnifying", "dismissive", "demeaning", "dehumanising", "devastating", "denouncing", "insulting", "cold and impersonal." It is an "illness with a person attached", "straight in your face [with] no compassion", a "communal label", "a pigeonhole used by doctors" "not acknowledging other parts of the persona", "a blanket term" which "blurs person and disease", "suggests that the person is locked in their illness inescapably", "lumps everyone together without allowing for the very many different ways that people behave" and "makes the person invalid." 'Schizophrenic' is "like a threat." It "stands out", "jumps on you", "makes patients feel mad" so it is "harmful to the person." It implies that the illness "dominates the person completely" who "will never be anything else." It "does not give a chance to people to be normal", "gives the rest of society a licence to behave badly towards them" and "takes away a sense of caring and responsibility from individual to individual." "The person is distant, not a first or second person but a person spoken about."

Confronted with this identity offered by the medical establishment and society, patients had four options. The first one was to take on the language of the medical establishment or the identity projected by society, albeit sometimes with qualification: "I have no objection to this name [schizophrenic] as long as it is an appendage name." A small minority of the patients defined the word in relation to hospitals and treatment: "'Schizophrenic' is somebody who has been to hospital", "waiting for a possible cure." And "It has a social function. It's a way of educating people. It shows to other people what schizophrenia is like so they could recognise it in
themselves. Also, it’s a way of self-monitoring to see what’s happening to oneself.” Some relatives too followed this line of discourse: “I would use it with qualification, e.g., diagnosed as schizophrenic in hospital.”  “It is important for people to face the fact of schizophrenia head-on. Circumlocution is, to some extent, an evasion and devaluing.” “Schizophrenic’ is honest and truthful. If I have cancer they do not find another name for it [otherwise] how can people face it?”

Some patients had introjected the image projected by society: “Because I have internalised it. This is exactly what happens out there. They put people in little boxes.” “It means mad people... I am used to it”, “because it’s the term that I know and it’s being used.” “That’s the way people call them so I call them the same way”, said a patient. “‘schizophrenic’ is a term used by me as I know so many [people] called ‘schizophrenic’ just as I am.” Patients and relatives sometimes resign to whatever way they are described: “Those who use ‘schizophrenics’ are not really concerned they’ll be viewed in a bad light or not. When I am tired I [myself] do this” and “This is...what people would say anyway and I would accept it.”

The second option was to use the ‘tool’ for antistigmatising or compensatory purposes under the justifying discourse of precision, straightforwardness, simplicity, correctness and appropriateness. “‘Schizophrenics’ because it is grammatically correct.” “It describes absolutely the condition of the sufferer...It’s clear, concise, to-the-point and leaves no margin for error.” “It explains my condition. It means long-term and it is easier.” “It is most expressive to people who have not got the experience.” “It’s straightforward...and more appropriate” “You can see a body ailment but not a mind [one] as the mind is different from the body although the two are one.” One has to be straightforward as otherwise, according to a relative, one “was not sure if the person had got it.”

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The straightforward use of the term would lead to getting social security benefits and compensation and the necessary care and help to reduce the effects of deprivation caused by stigmatisation: “[I say] ‘schizophrenic’ because on income support book they described me as schizophrenic.” “I do not function as well as some people” It is “the statement of madness.” “It is protective. It means incurable”, “the person is considered ill and helped more.” This is especially true for the unemployed and possibly lower social classes who are likely to gain economically rather than lose as opposed to higher social classes where the preservation of the existing economic status by hiding the diagnosis outweighs the attraction of material benefits gained with the help of the diagnosis. A relative commented: “we are working class. We do not really worry about it. In a middle class neighbourhood it is more important to be respectful and cover things up.”

The use of designations for compensatory purposes is an antistigmatisation defence mechanism for securing material advantages in order to survive in the midst of deprivation and inequality yet the adopted identity cannot always be without effects on the underlying self-esteem. This undermining of self-concept is a secondary consequence of use of the designation for compensatory purposes. Estroff (1981) proposes that this process may contribute to the perpetuation of ‘a mental patient’ identity. Despite the damage the attribution causes to their self-concept, it happens that social services provide them with material benefit by virtue of the same attribution. In the middle of their misfortune, they have only their label, i.e., the representation of a damaged identity, in order to gain material benefits which are going to partially compensate for the deprivation caused by stigmatisation though, at the same time, perpetuating the ‘mental patient’ identity.
Another antistigmatising defence tool is to use the term ‘schizophrenic’ for revalorisation — reclaiming the lost sense of personal value, normality and intelligence as a means of withstanding stigmatisation. As this study showed, the instances where patients consider a label as ‘not much devaluing’ are related at times to their attempt at reclaiming positive connotations for a devalued attribution, rather their proclaiming that they have not been in effect harmed by the label. [I refer to them as ] clairaudients”, “quite creative; amusing”, “brainy”, “fit people”; “interesting”; “human beings”, “good people”, “normals”, “bosses”; They are “individuals who are normal in every way despite the illness.” They are “going through certain trials in life in order to gain strength.” “I think schizophrenics are blessed”, “they are children of God.” One has to emphasise that these patients were in remission and the content of their discourse cannot be related to delusion, though even if it could, the content of delusions are not devoid of current wishes, feelings and needs of patients.

There were also indications of reclaiming in relatives on behalf of patients: “schizophrenia is not a terminal illness.” “Schizophrenics’ means paranormal, mystic people with psychic powers”, “enlightened”, “good people”, “human being”, and “quite clever.” The reclaiming was not limited to the word schizophrenic. ‘Person with schizophrenia’ means “intelligent and able” and ‘person having schizophrenia’ brainy. And slogans: “A person has value whether with a disease or not.” “It’s mad to be normal and normal to be mad. I prefer mad!”

Another antistigmatising defence tool was to use ‘schizophrenic’ for solidarity purposes. This will be discussed in the following section.
6.1.5 Solidarity as a Defence against Stigmatisation

Solidarity with other patients was reflected in how patients or relatives referred to them “Babe, friends, mates, fellow, ‘hoahman’” [sic]. “I’d say] someone I was in hospital with. Someone I know in the day centre who is schizophrenic.” “[I’d say] I am your dado [nearest companion].” “Schizophrenics are my mates.” Also, “people with schizophrenia are different. You feel it once you meet them.” “I feel something in common with them. I consider them comrades.”

The medical establishment was at times spared from the discourse of solidarity presumably in order not to sacrifice their therapeutic distance or technical understanding of the illness: “Only doctors can refer to them [as schizophrenic]; others [should say] friends.” “Doctors can use their own terminology to describe different cases. Not for everyone to use [these terms] who don’t have a medical education.”

Some patients wished to use only one designation to politicise their affliction as a matter of solidarity. “I prefer ‘schizophrenics’ to the other labels because it groups all people with schizophrenia together and does not distinguish between one or the other.” “I prefer to be called ‘schizophrenic’ because it sounds [more] like a friendly term.” “When we talk with other schizophrenics we call each other ‘schizos’ for solidarity.”

A few relatives could empathise with patients by their own experience of mental illness. The girlfriend of a patient said: “I’ve felt a freak for years and years. When I was in a bad way and needed help I went into hospital and they plonked a name on my forehead that was the last thing
I needed... My name being 'manic depression' has affected my self-image and self-esteem. It has caused a lot of pain, self disgust. Just the whole way I feel about myself as a person.”

A considerable number of relatives referred to the illness in terms which included their familiarity or solidarity with patients. “Like Ted, my son.” “[They] bring my brother to my mind: troubled, disturbed, misunderstood, in need of support, completely isolated. People around him not able to help or cope.” “People who have schizophrenia are everyone who is like my son.” “They are those who have gone through the same sort of illness as my wife.” This discourse sometimes took the form of referring to anyone with schizophrenia with the title of the ill relative: “Mum.” A number of relatives said that they tend to be more sympathetic to other patients because of their own family member who was ill.

Relatives too wished, at times, to use one word in order to declare their solidarity with patients: “[I say] ‘people with schizophrenia’ because it is more user friendly” and “ ‘Schizophrenia sufferers’ because it brings them all together” and “because when I speak to people who suffer from schizophrenia they use this expression.” Sometimes patients or relatives requested more solidarity from the public: “I assume people are my friends. [I’d like] to encourage people not to be afraid of using the word [schizophrenia] because of being frightened of what it is.” “Say that I have the illness but refer to me normally... Involve me in normal conversation...”
6.1.6 Re-conceptualisation of Schizophrenia as a Defence against Stigmatisation

It was common for patients and relatives to re-formulate notions of schizophrenia in describing patients: "unwell", "unbalanced"; "twin personality"; "mentally vulnerable; "not well" and "not well man." There was, at times, an attempt at deconstructing the illness into its components or symptoms: "I often describe them in accordance to how they come across. For example, I may describe them as ‘over-anxious’; ‘feeling self-persecuted’, ‘feeling insecure’ or ‘talking about things which they perceive as real’ ".

The re-conceptualisation of schizophrenia was, in some cases, associated with linguistic intervention in order to moderate any possible stigmatisation: “just a bit sick with mental health problems”; “having slight nervous breakdown. Hiccup in their equilibrium” or “someone with a problem”, “having a short illness” or “going though neurosis.” A relative reformulated the definition of someone with schizophrenia as “someone who needs to have a rest to sort out their life.” This was in other cases associated with the idea of treatment and/or treatability of the illness: “not well man” but “it can be cured.” “ ‘A person with an illness who can get better’ provided that he/she sticks to the medication.” Some formulations showed a dichotomy based on treatability or hospitalisation status: “If they can get out of it ‘paranoid schizophrenia’; if they cannot, ‘schizophrenic’ or ‘psychotic’ ”; “ ‘group of people’ if they are out of hospital. ‘group of patients’ if they are in hospital.” The latter is an example of re-conceptualisation by resorting to the concept of personhood which is going to be discussed in the next paragraph.
6.1.7 The Discourse of Personhood as a Defence against Stigmatisation

One important aspect of the re-conceptualisation of schizophrenia was a variety of linguistic intervention to emphasise patients' personhood while reformulating the diagnosis. The common belief among patients and relatives was that patients should be treated as 'people': "psychiatric people", "people with an illness", "people with mental illness", "people who have trouble with their nerves." "people with schizophrenia", "people living with schizophrenia", "A person who has schizophrenia", and "people who have an experience of schizophrenia." They believed that these expressions did not claim defining the whole person contrary to other expressions which seemed to indicate that the patient was totally defined by the illness and there was no more to be said about their character. A relative commented: "It's actually difficult to separate person and disease in schizophrenia but it is sometimes necessary" to do so in order to "recognise the person as a member of the community."

It was interesting that some patients, to make sure that personhood remained the essence, intervened in language to precede illness by people: "people ill!" 'Person' preceded the illness "because I am the person with the illness not the illness itself."

Some patients and relatives avoided any technical lexicon while at the same time emphasising personhood: "[I call them] person", as "people who need care." "It's hard to find an adequate word to collectively associate them but generally I see them as 'people who are struggling with an aspect of their life' " or "people who have social problems", "people with a change in their
And “I try not to categorise them as a group. Most of the words used to describe someone with schizophrenia have a negative meaning.” “You don’t call someone cancerous because he/she has cancer.” Reference to patients’ personhood was frequent in relatives’ discourse too: “people who need help and guidance”, “ordinary people”, “special needs people”, “people who one feels sorry about.”

Patients’ responses suggested their belief that introducing the notion of personhood was “gentle”, “compassionate”, “sympathetic”, “mild”, “soft”, “positive”, “kind”, “more neutral”, “less branding”, “less aggressive”, “less definite”, “less heavy”, “less patronising”, “least offensive”, “not too pervasive”, “not too alarming” and “almost normal.” It meant “suspect of being ill”, allocated “less responsibility”, attracted “help” and implied “more respect than judgment” and “the need for special treatment and understanding.” “I would be understood and excused, to some extent, for my behaviour.”

Including the notion of personhood also suggested universal vulnerability to the illness: “anyone can develop it.” Bringing in personhood with all its connotations of value implied partialness and temporariness of schizophrenia rather than its predominance and permanence and suggested that the illness could be cured. Relatives generally thought that person with schizophrenia and/or person having schizophrenia were “trendy.” They were so because they meant that “schizophrenia is not me...not the core of me” and because “you are not directly telling someone about his illness.” Also ‘being with something’ and not being aware of it was different from “wanting something.” The illness may be only a small component of patients’ lives and so using the term “would meet with less irrational responses” as it implied that they (patients) did not always have to be with it.”
Some patients showed at times a tendency to shift their expressed attitudes depending on the ideological position of the social group they met. This indicates some patients’ occasional vulnerability in giving up to social pressure when threatened by rejection and stigmatisation: “[I say] ‘people with severe mental illness’ when I am talking to people who are sympathetic’. [I say] ‘schizophrenics’ when talking to ordinary people who regard schizophrenics as ‘them’ not ‘us.’ I take a view about people I am talking to.”

From a completely different perspective, juxtaposing personhood and schizophrenia meant to some patients that the person was going to be “infected” as if by something “contagious”: “[They] imply something you can catch or something that only ‘other people’ can get.” “As if a bacteria has infected them.” “[People with schizophrenia is like saying] a whole lot of people with HIV.” This idea of being ‘infected’ was also linked to other expressions: “Schizophrenia sufferers’ implies to me that they are plagued by the condition.” The discourse of some patients showed how much they consider the condition to be ‘infective’, in the sense of stigmatising and sullying their name: “I want to clear my name from schizophrenia one day.”

The idea of infection and catching the illness was also present among relatives: “‘People with schizophrenia’ sounds as if the person...can catch it”, “Like a virus.” This represents the relatives’ belief about what can infect them as well. Something rubs off and contaminates whoever is somehow connected or comes in touch with the patient. The relatives takes on something of the illness, some infamy or stigma that is going to infect them like a microbe.

The same juxtaposition of personhood and illness also meant to some patients that the person was loaded as if with a heavy weight — a burden. This implied “a difficult result”: “they’ve got a
baggage they cannot take off” or it sounds “like the illness belongs to them or is part of them.”

This meant “getting let down”, “being punished by society” and “being pointed out” with something. The concept of personhood being loaded with a burden also meant to some patients and relatives “born with schizophrenia (equivalent to race or a congenital disease).” A number of relatives were concerned about genetic research into schizophrenia. Their concern was likely to be linked to how this type of research could prove them to be loaded with a fault: “Genetic research with its claim to the hereditability of schizophrenia could have stigmatising power.”

For still other reasons, the juxtaposition of personhood and illness was unappealing to some relatives. “schizophrenia is presumably an absence of something so one cannot have it.” It also implies “as if the patient has actually chosen to be schizophrenic.” It is also “impersonal [as] it does not allow easily to add the first name.” Hence the opinion that these expressions are not “felicitous” or “grammatical” and are “removed from day to day understanding.” They sound “false”, “un-natural”, “patronising”, are “too wide, long, wrapped-up and woolly”, “pedantic”, “rude” and “morbid”, “distant, with a desire to hold back from that person”, “alienating and impersonal” and even “antisocial.”

Frustration ran high among patients about their ‘designations’. “Diagnosis is a name.” “I wish one could find a new term for it to throw away all the baggage of accumulated stigma associated with it” or “I wish I was not bom having schizophrenia.” Some patients intervened to create new names for themselves: “For me, special name ‘Boysee’! Others by their own made-up names!”

“People with a condition should not be described by that condition.” [I refer to them] “by their Christian names.” “I would be concerned if they call them mad.” And another patient: [I’d like
them to call me] “Willy.” And another patient: “He, she, they”; “Bob, Jane, etc.”, “as they would call anyone else.” And the sympathy needed on top of calling patients by their name: “By their first name.” [And also] “I speak very kindly to them.”

6.1.8 Denial as a Defence against Stigmatisation

In some cases there were indications of attempts by patients to deny or avoid the idea of having the illness: “You can always have a conversation. You can get round it, persuade people you do not have it.” “I don’t tell people about my condition. Tend to avoid people who know about [it]. They imply I am not doing what the rest of society is doing. It’s like a label which is stuck on [me] as if I am going around with lots of rubbish.” “No one knows what schizophrenia is”,” people are not sure of [any] illness. Just suffering.” “I don’t ever speak about other people who suffer schizophrenia”, “we are all in hiding.”

Denial of the existence of schizophrenia was seen in relatives as well: “I don’t believe that schizophrenia is anything. It’s [just] a convenient label.” This took at times the form of a new explanatory model: “They are people with different perceptions. People who have difficulty in expressing their perceptions. People with different analysing methods”, “people who have difficulty in separating mundane reality [from] imagination.. There is still so little known about mental problems I prefer to regard these [just] as ‘differences’.” Also, “I avoid the word ‘schizophrenic’ because I do not now what it is.” “I do not talk to anyone about it.” “[It is] a general condition rather than a specific illness and as far as I know it describes behaviour rather than illness.” “In the climate of Britain today, depending on the person speaking and the person
Sometimes belief in the efficacy of treatment or recovery was used to assert that schizophrenia did not exist: “On medication they are stable. With counselling and psychotherapy they can lead a normal life. I do not agree that schizophrenia exists. I don’t basically believe in schizophrenia. I have not been ill since the psychotic episode so I am not schizophrenic.”

6.1.9 Exclusion of Patients as a Defence against Stigmatisation

In my survey, as expected, the exclusion of other patients was present but uncommon. A few patients had categorical views about other patients possibly in order to avoid being assimilated into a group already a target of social stigmatisation: “[They are a ] pain in the neck. I can’t go along with them. There are different levels of schizophrenia.” “[I call them] mad, crazy.” Elsewhere in response to the question ‘how would you like other people to call those who have schizophrenia if, by chance, you yourself developed schizophrenia’, the same patient responded: “Sick people” as such locating himself in a different category. A patient who was attending a depot clinic said: “Schizophrenia-sufferers attend depot clinics, schizophrenics [are a] completely independent group waiting for a possible cure. They take tablets.” Another patient said: “I do not socialise or mix with mental health patients.” This took sometimes the form of ‘not wanting to know’ rather than strictly speaking stigmatisation: “I have enough pain of my own to know what they have suffered.” Also, “some people have genuine schizophrenia. Others are made to suffer because they have fabricated their mental illness.” And “‘Schizophrenia sufferer’ is off-putting...Some of it is needless. Some people suffer without any need to suffer” and “they keep
pestering themselves.” “[I call them ‘schizophrenia sufferers’] because they are different from me. They are more ill.” Sometimes exclusion and stigmatisation depended on whether the fellow patient would take their medications: “normal when they’ve got their tablets, nasty if they don’t take their tablets.”

A few relatives tended to think that “schizophrenics may have extremely violent tendencies towards themselves and others.” Another relative commented: “Mad. People are frightened to be in their company.” “Mad. Yes. I consider my son as mad.”

On the whole, stigmatisation as a defence against stigmatisation was not very common but constitutes an important discourse that will again be discussed in the results of linear regression of stigmatisation scores.

6.1.10 Universality of Suffering as a Defence against Stigmatisation

Reference to the idea of having “a hard time”, “suffering” and “broken heart” was common in the patients’ discourse: “ ‘People with schizophrenia’ means people with a broken heart.” “I would like someone who has schizophrenia to be acknowledged as a human being who, having experienced an enormous amount of pain has a broken heart. “ ‘Schizophrenia sufferer’ means it’s a form of pain” and “It hurts” and “[this is] a true statement.”

Patients in general considered the expression ‘schizophrenia sufferer’ to be “less labelling”, “least bad sounding”, “kinder”, “more friendly”, “more human verbally”, “more compassionate”, “more
polite”, “more likely to be accepted by people”, “not so loud, not a big word”, “very gentle”, “inducing empathy”, and “correcting the idea of patients’ wanting to harm others.”

Suffering is associated with human life so it implies the universality of the illness: “‘Schizophrenia sufferer’ means an illness anyone can suffer from and it is not only for certain people.” Also, it implied temporariness, gradations in severity and so hope for recovery: “It [also] means an illness of varying degrees” which “comes and goes” and “is not permanent” and “can be cured in some cases” or at least “he can force himself to get better.” And innocence: “The person suffering is not evil.” It is “an illness” that “stresses the person.” [It is] “not a crime.” And lack of agency and responsibility, at times expressed implicitly: “‘Schizophrenia sufferer’ [means] it just happened. Only God knows these things.” “[It means] it’s not their fault. It’s not in their control. Not of their own volition.” “I am a sufferer. I don’t like hearing voices. It’s not my fault.”

Though de-emphasising agency, these patients believed that the term was more conducive to hope and ownership of the illness than other terms such as ‘schizophrenics’: “I don’t know the exact meaning of ‘schizophrenics’ but that frightens me. If I ‘suffer’ from or ‘have’ schizophrenia, I would try to own my illness and try to understand.” ‘Schizophrenia sufferer’ “does not actually brand you” and “does not necessarily say you’ve got it.” “It’s like a second chance to be in the world again” and “it opens a door to go out.”

The same discourse of suffering conveyed not only the pain of schizophrenia but also the pain of its stigmatisation: “Schizophrenia ‘sufferer’ because those who have this illness must be frustrated with [it] and [also] the response they get from others.” And the pain of its treatment: “‘Schizophrenia sufferers’ because they also attend depot clinics and they have been suffering
The discourse of suffering was considered by patients to attract help and dissipate stigmatisation. “It would give the public an incentive to try to help them rather than give them more problems.” “[People] in the streets call us ‘nutters’. When someone shot [some] children I was worried there would be a backlash on people with mental illness.” “People think we are dangerous or a threat to other people. ‘Schizophrenia sufferers’ shows we are suffering” rather than “inflicting something on others. It conveys [this] better to people who do not know.”

It is striking that patients are at times so helpless in confronting stigmatisation that they seem to get hold of any means they have to confront it. One of these means is the fear that stigmatised terms can create: “When some considerate people hear about a ‘sufferer’ they may be less inclined to exploit me, lest I may react violently towards them.”

Relatives’ discourse included some elements similar to patients’ discourse such as the universality of illness and suffering — “the illness is no selector of persons”; the lack of agency — “They don’t choose to suffer”; the anti-stigmatising impact of the discourse — the person is more likely “to be pitied than mocked”; the attraction of help — “[It means] “in need” and implies they are “types of people”, “human beings”; and temporariness and hope for recovery — “[It means] just for a period of time” which “makes me feel better so I overcome the illness.”

Relatives also believed that the discourse of suffering makes the illness more visible: “I do realise that some people can suffer for years without anybody realising. The person is suffering within that illness but is not ‘mad’ all the time.” “If you say suffering [it becomes like] a physical illness
you can see” Also, suffering leads to salvation: “[If I develop schizophrenia, call me schizophrenia sufferer] as God will take me to heavens.” They will go to heavens as they are “victims not monsters.” They “go through a traumatic episode without knowledge of the meaning of schizophrenia.”

A relative commented that designations were not “value free. They have been taken with a particular type of cultural baggage which may prevent clear observation and assessment. So all should be modified if possible” so, in the same way that some patients intervened in language by changing ‘ill people’ into ‘people ill’ to precede illness by personhood, relatives at times preferred ‘a sufferer of schizophrenia’ to ‘schizophrenia sufferer’ as in the former the word schizophrenia would not come first “to make people jump.” A step further for the relatives was to completely wipe out the name of the illness and fill it with silence, an absent lexicon: “a sufferer of....”

From a different perspective, a minority of patients shunned the idea of suffering. They considered ‘schizophrenia sufferer’ to be too formal, “an official social label”, carrying “chronic”, “hopeless”, “heavy”, “definite”, “patronising” and “ridiculous” connotations and also implying that patients are suffering more than they really are. “I don’t like the idea of suffering and being ill”, also “schizophrenia sufferer’ make you think that the person is more mentally ill [than they are].” “Sometimes you don’t suffer with it. The voices could be nice.” Further “The sufferer would not like to be referred to as ‘schizophrenia sufferer’. He does not want to be reminded that he is even worse.” ‘Schizophrenia sufferer’ “makes people out to be passive and pitiable” and means they are “unpredictable” and “sick.”

To some relatives the expression ‘schizophrenia sufferer’ meant taking away patients’
responsibility to have it treated. It was “sentimental and unrealistic”, meant that the person was “very weak” and did not “convey a degree of dignity.” Also it suggested that the patient was “a victim...the butt of divine retribution” or “made guilty by society.” It puts people “in a category from which it seems they can’t escape” and “segregates them from ordinary people.” “A group of people one must stay away from: [people] murmuring. Speaking on their own.” The idea of infectiousness and contagion surfaces again, this time in relation to ‘schizophrenia sufferer’: It was “as if there were something contagious others should keep away from” as if schizophrenia sufferer is “not somebody close, a stranger, a third party...”

6.1.11 Discussion

The patients’ and relatives’ testimonies provide valuable information about their concerns, experiences, feelings, anxieties and explanatory models. As it is clear from the above, there are main patterns in patients and relatives’ discourse but also an array of diverse lines of discourse belonging to subgroups of patients and relatives about the meaning and significance of schizophrenia to a degree that almost for any given opinion there is a contrary one expressed by another person. To be effective, treatment models, service delivery and communication with patients and relatives must take account of their individual explanatory models.

No single designation was considered to be totally acceptable to all patients or relatives. This is interesting because if such a term had ever existed the debate on patients’ and relatives’ anxieties expressed in their discourse would have ended. The group of patients and relatives by not pointing out a single designation which would be acceptable to all of them were declaring that the
debate concerned some unresolvable difficulty in their relationship with the world. The community of patients consulted were declaring collectively that referring to patients, in a manner satisfactory to all of them, was an impossible task as they would anyway locate their dissatisfactions, conflicts and anxieties about their position in the world in any linguistic representation.

It was such that the discussion on these representations could open the door to their discourse: their beliefs, feelings, attitudes, fears and stance on the illness. This was rewarding as beyond negotiating an appropriate term to refer to patients, the examination of patients’ and relatives’ discourse about schizophrenia was one of the major objectives of this part of the study. The real question is not “So, how should we call the patients?” inasmuch as it seems that there would always be patients and relatives who attach their anxieties about whether their condition is going to be permanent, whether it is going to be curable, and whether they are going to be accepted or remain “forever lonely and mad” etc. to these different terms. Their discourse about the meaning of these terms were indeed a mirror reflecting a fundamental concern: whether they were going to be freed from the social burden of schizophrenia.

On several occasions the notion of ‘schizophrenia’ was linked with the idea of hospitalisation or being in hospital as opposed to being out of hospital. This is compatible with previous research that has linked the importance of hospitalisation in identifying a person as mentally ill (Johannsen, 1969, Scheper-Hughes, 1987). My report confirmed parts of Scheper-Hughes’ work in that, for example, the denial of mental illness in Irish-American relatives of patients in a South Boston Community in the USA and her quoting an Irish-American patient who would not wish to accompany a group of patients to the library or a bowling alley as she did not want to be seen in
public "with a bunch of nuts" (p. 68), probably as a defence against stigmatisation.

As the analysis of patients' discourse suggests, they have different linguistic preferences so mental health workers and patients can discuss the latter's individual choice as a means of both showing respect for the patient's discourse and establishing therapeutic rapport. Clinicians and other mental health workers need to incorporate the opinions and attitudes expressed by patients and relatives in their therapeutic programme and, as each person is unique, be willing to enquire about and discuss patients' and relatives wishes, anxieties and preferences. It is in this way that a better understanding of stigmatisation may become possible and patients and relatives' empowerment and participation more of a reality.
CHAPTER VII

FACTOR ANALYSIS
7.1 Perception of Stigmatisation and Predisposition to Enact Stigmatisation in Patients and Relatives

7.1.1 General Trends

On the perception of stigmatisation, with a possible maximum raw score of 52 on the final 13 items derived by factor analysis (see chapter VII), the mean for patients and relatives was 34.3 with a standard deviation of 6.3. A high score represented a strong perception of stigmatisation. About 90% of the participants scored above the midpoint of 26. This means that the majority of participants perceived a relatively high degree of stigmatisation presumably causing them considerable concern. This was corroborated by an analysis of patients and relatives' discourse. The same was true for perception of linguistic stigmatisation with a possible maximum raw score of 16, a mean of 9.9 and standard deviation of 3.4. About 70% the participants scored above the midpoint of 8.

On predisposition to stigmatise, with a possible maximum raw score of 52, the mean for patients and relatives was 24.9 with a standard deviation of 5.8. A high score represented a higher predisposition to enact stigmatisation. About 64 percent scored below the midpoint of 26. This means that 64% of the patients and relatives declared they had a relatively low tendency to stigmatise. When stigmatisation scores were considered separately for patients and relatives, the figures turned out to be very similar to those when all the participants were considered together.
7.1.2 Areas of the Highest Frequency of Stigmatisation

As mentioned in the chapter IV, the questionnaire incorporated a vignette about a man who becomes ill. The succeeding questions were organised in two parts: part I contained twenty questions assessing perception of social stigmatisation and part II twenty questions assessing predisposition to enact stigmatisation by the participants. Table 7.1 shows six areas with the highest frequency of perception of stigmatisation in patients and relatives. Those participants who gave a response of ‘Yes, a little’ or ‘Yes, very much’ were re-grouped under ‘Yes’ and those responding ‘No, not much’ or ‘No, not at all’ under ‘No’.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Patients' Responses %</th>
<th>Relatives' Responses %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would most people be happy if he married their sister?</td>
<td>14.1 85.9</td>
<td>7 93</td>
</tr>
<tr>
<td>Would most people be happy if this person became the teacher of their children?</td>
<td>18.5 81.5</td>
<td>4.7 95.3</td>
</tr>
<tr>
<td>Would most people be happy if he were to work together with them in their workplace?</td>
<td>38 62</td>
<td>13.3 86.7</td>
</tr>
<tr>
<td>Do most people think he is very likely to become physically violent?</td>
<td>79.3 20.7</td>
<td>85.9 14.1</td>
</tr>
<tr>
<td>Would most people be frightened if this man came to live next door to them?</td>
<td>72.8 27.2</td>
<td>82 18</td>
</tr>
<tr>
<td>Do most people think he has become a failure in his life?</td>
<td>65.2 34.8</td>
<td>57 43</td>
</tr>
</tbody>
</table>

Table 7.1 Patients and relatives' responses to the six questions which showed the highest frequency of perceived stigmatisation.
The high percentage of patients and relatives perceiving stigmatisation in the area of exclusion from transactions (such as work, marriage, teaching, neighbourhood) suggests that this area does not explain the highest proportion of variability of the dependent variable (score of the stigmatising attitude). This means that most patients and relatives responded to the relevant questions with unanimity. The same was true of the questions on perception of patients' violence or the perception of their failure in life (Table 7.1). To discover the factor(s) that explain(s) the highest variability of stigmatisation one needs to apply factor analysis to the results which will be discussed later in this chapter.

In part II of the questionnaire, in order to assess patients and relatives' stigmatising attitudes towards patients, participants were asked how they would have reacted to the same man described in the vignette: ‘Would you be happy if he married your sister?’ etc. (Tables 7.2 & 7.3). The majority of patients and relatives acknowledged they would stigmatise in the area of transactions: teaching (61% of the patients and 73% of the relatives) and marriage (60% of the patients and 80% of the relatives) and responded to the relevant questions with quasi unanimity. This means that even patients and relatives despite their familiarity with schizophrenia and solidarity with patients (see below) were unwilling to enter into serious transactions with other patients at least in the area of marriage and teaching.
This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.

<table>
<thead>
<tr>
<th>Patients' Response</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you be happy if this person became the teacher of your children?</td>
<td>39.1</td>
<td>60.9</td>
</tr>
<tr>
<td>Would you be happy if he married your sister?</td>
<td>40.2</td>
<td>59.8</td>
</tr>
<tr>
<td>Would you be willing to work in the mental hospital where he is treated?</td>
<td>63</td>
<td>37</td>
</tr>
<tr>
<td>Do you think he is very likely to become physically violent?</td>
<td>45.7</td>
<td>54.3</td>
</tr>
<tr>
<td>Would you be frightened if he came to live next door to you?</td>
<td>33.7</td>
<td>66.3</td>
</tr>
<tr>
<td>Do you think one of the main causes of his condition is a lack of moral strength or will power?</td>
<td>29.3</td>
<td>70.7</td>
</tr>
</tbody>
</table>

Table 7.2 Patients' responses to the six questions which showed the highest frequency of predisposition to enact stigmatisation by the patients.

<table>
<thead>
<tr>
<th>Relatives' Response</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you be happy if he married your sister?</td>
<td>20.3</td>
<td>79.7</td>
</tr>
<tr>
<td>Would you be happy if this person became the teacher of your children?</td>
<td>26.6</td>
<td>73.4</td>
</tr>
<tr>
<td>Would you be happy to work with him in your workplace?</td>
<td>66.4</td>
<td>33.6</td>
</tr>
<tr>
<td>Would you be happy to work in the mental hospital where he is treated?</td>
<td>72.7</td>
<td>27.3</td>
</tr>
<tr>
<td>Do you think he is very likely to become physically violent?</td>
<td>40.6</td>
<td>59.4</td>
</tr>
<tr>
<td>Do you think that, because of his condition, his wife should be allowed to divorce him without his consent?</td>
<td>39.1</td>
<td>60.9</td>
</tr>
</tbody>
</table>

Table 7.3 Relatives' responses to the six questions which showed the highest frequency of predisposition to enact stigmatisation by the relatives.
What is important is that, as the above results suggest, in both perceived stigmatisation and predisposition to enact stigmatisation, questions which attract a stigmatising response in a higher percentage of participants tend also to have a high 'self-interest value' (physical safety, genetic self-interest, etc). This supports the self-interest hypothesis embedded in the unitary theory of stigmatisation described earlier.

7.1.3 **The Disparity between Participants' Perceived Stigmatisation and Predisposition to Enact Stigmatisation**

When the scores of each question on participants’ perception of social stigmatisation were compared with the scores of the matched question on participants’ stigmatisation of other patients the differences were statistically significant for each pair of questions with the first scores being systematically higher than the second ones both for patients and for relatives (Wilcoxon signed rank test, P < 0.0005). For example, patients (or relatives’) responses to the questions *Would you be happy if he married your sister?* are stigmatising in the sense that nearly 61% of the patients (and 79% of the relatives) say that they would ‘stigmatise’ in this area, yet the difference with the stigmatisation perceived by patients in society in the same area is statistically significant in that patients believe that society would stigmatise more than them in the same area (Tables 7.1 and 7.2). This was true for all the twenty Likert questions assessing perceived stigmatisation when they were compared in matched pairs with the twenty Likert questions assessing predisposition to enact stigmatisation using Wilcoxon signed rank test (P < 0.0005, two-tailed, for any given pair of questions). For example, when the Likert score of patients’ (or relatives’) responses to *Would you be happy if he married your sister?* was compared to responses to *Would most people be*
Would you be happy if he married your sister? Vs. Would most people be happy if he married their sister? Patients' Responses

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Rank</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative Ranks</td>
<td>41</td>
<td>28.17</td>
<td>1155.00</td>
</tr>
<tr>
<td>Positive Ranks</td>
<td>12</td>
<td>23.00</td>
<td>276.00</td>
</tr>
<tr>
<td>Ties</td>
<td>39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Wilcoxon Signed Rank Test Statistics

\[ Z = -4.030; \; P < 0.0005 \]

Table 7.4 A comparison of perceived stigmatisation and predisposition to enact stigmatisation by patients in the area of marriage. The perceived stigmatisation is significantly higher than the predisposition to enact stigmatisation by the patients themselves.

Would you be happy if he married your sister? Vs. Would most people be happy if he married their sister? Relatives' Responses

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Rank</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negative Ranks</td>
<td>56</td>
<td>34.98</td>
<td>1959.00</td>
</tr>
<tr>
<td>Positive Ranks</td>
<td>11</td>
<td>29.00</td>
<td>319.00</td>
</tr>
<tr>
<td>Ties</td>
<td>61</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>128</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Wilcoxon Signed Rank Test Statistics

\[ Z = -5.558; \; P < 0.0005 \]

Table 7.5 A comparison of perceived stigmatisation and predisposition to enact stigmatisation by relatives in the area of marriage with a patient who has developed schizophrenia. The perceived stigmatisation is significantly higher than the predisposition to enact stigmatisation by the relatives.

- a. Participants' predisposition to enact stigmatisation of their sister marrying another patient < Participants' perceived stigmatisation by people of their sister marrying a patient
- b. Participants' predisposition to enact stigmatisation of their sister marrying another patient > Participants' perceived stigmatisation by people of their sister marrying a patient
- c. Participants' predisposition to enact stigmatisation of their sister marrying another patient = Participants' perceived stigmatisation by people of their sister marrying a patient
- d. A higher negative Mean Rank indicates a lower degree of enacted stigmatisation.

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happy if he married their sister? the following results were obtained (Tables 7.4 & 7.5). These results indicate that patients and also relatives report having a significantly less intense stigmatising attitude than the one they perceive as the society’s stigmatising attitude in all the twenty domains explored by the questions in the survey. In other words in response to all the questions they reported a significantly lower stigmatising attitude in themselves than in society. The results remain the same whether all the original 258 participants are included in the computation or only those with low SD scores (n = 220) are included.

It is possible that patients and relatives by virtue of their familiarity with the pain and suffering inherent in schizophrenia, their better understanding of the harmful effects of stigmatisation and solidarity with patients are prone to stigmatise significantly less than most people do. This argument is compatible with previous reports (Philips, 1963; Taylor & Dear, 1981; Brockington et al, 1993; Serrano-Prieto, 1995) indicating that those people who had personal experience of mental illness or had a friend or relative affected are less rejecting of patients than other people. It is also possible that patients and relatives’ claim that they stigmatise less is at least partly indicative of human bias in identifying ‘society’, ‘other people’ etc. as stigmatisers and themselves as a better version of a human being and this is likely to be true for people other than patients and relatives as well.
7.2 Factor Analysis

7.2.1 Introduction

Factor analysis is a method that helps reduce data to its essential components. For example, it looks at responses to all the questions in a questionnaire, prunes the data that do not seem to be essential and regroups and summarises the essential ones. Strictly speaking it needs an interval scale of measurement but it is commonly applied to ordinal scales such as Likert assuming that the distances between points on the scale (Yes very much; yes a little, no not much; no not al all) are almost identical.

One of the most interesting features of factor analysis is that it extracts sets of questions, which seem each to be measuring an underlying tendency, attitude or concept, in the form of components called FACTORS. Each factor is presumed to measure an underlying attitude, a non-observable, hidden construct it brings to the surface while also quantifying its contribution to the total variability of what is measured. Factor analysis determines a number of factors equal to the number of items, in this case, the questions of a questionnaire. For a 20 item questionnaire, 20 factors will be extracted at a first stage.

Principal component analysis is a method of factor analysis. It singles out the principal factors contributing most to the total variability of what is being measured. The share of each factor in explaining the total variability of, for example, stigmatisation shows how much of the variation of stigmatisation can be explained by the scores of the attitude underlying each factor alone. The
first factor represents the highest share of the total variability of the dependent variable (stigmatisation), the following factors lower shares of the total variability.

Each of these factors extracted by the principal component method is composed of items (questions of the questionnaire). Each item has a loading figure which is representative of the correlation between that item and that factor. The higher the loading the stronger the correlation between the item and what the factor represents.

Varimax rotation is a method of transformation of the loadings of the items in factors selected by the principal component method. It provides new loading figures for the items, based on introducing in the computation only those factors selected by the principal component method rather than all other factors which do not significantly contribute to the total variability. This makes the loading of each item of the factor more prominent and interpretable. Within each factor the scores of the items with higher loadings (usually above 0.500) could be combined and the resulting score be used as the measure of the underlying attitude.

Following factor analysis, reliability analysis is used to verify whether factors selected by principal component analysis and varimax procedure are each a reliable measure of an underlying attitude. Reliability is a measure of consistency of the measure by a factor. In examining the reliability the Corrected Item-Total Correlation is the correlation between an item and the total score of the remaining items in a factor. The higher the correlation the stronger the relationship between the item and the remaining items making up the factor and the higher the reliability. Cronbach Alpha is a measure of total reliability of a factor, i.e., the internal consistency among its items, and its value ranges between 0 and 1.
Following varimax rotation procedure, items with the highest loading in each factor are suggestive of the concept, attitude or tendency underlying that factor. As such, factor analysis and varimax rotation lead to an understanding of basic attitudes contributing to stigmatisation and so could have significance for delineating its origins as these basic attitudes are likely to be linked to fundamental motives for stigmatisation. Factor analysis also determines how many of the questions of a questionnaire are valid (measure what they are supposed to measure). As such the outcome of factor analysis can be used to check the validity of a questionnaire as well. Following factor analysis, the scores of the participants for each extracted factor can be subjected to linear regression with sociodemographic factors to discover any significant relationship between the latter and the stigmatising attitude represented by the factor and the proportion of the total variability of the factor score contributed by each sociodemographic variable.

7.2.2 Factor Analysis of the Attitudinal Questionnaire

Factor analysis was carried out on responses to the twenty questions on perception of stigmatisation and the twenty questions on predisposition to enact stigmatisation separately. Principal component analysis followed by varimax rotation revealed that the data in the areas both of participants' perception of social stigmatisation and predisposition to stigmatise other patients can be represented by three main factors accounting for nearly 50% of the total variance. Ideally this figure should be around 70% of the total variance yet a figure of 50% is moderately good.

In the area of perceived stigmatisation, factor one accounted for 32.75%; factor two for 10.71% and factor three for 5.52% of the total variance. The indicates that at least half of what the
questionnaire measures as stigmatisation can be located in three factors each based on an underlying attitude.

In the area of enacted stigmatisation, factor one accounted for 27%, factor two for 10% and factor three for about 6% of the total variability in predisposition to enact stigmatisation. There were two other factors extracted by the principal component method (each explaining about 6% of the total variability of predisposition to enact stigmatisation) but these two factors did not stand tests of reliability analysis on their items which had higher loadings. The three factors which were reliable were the same as those selected by factor analysis for perceived stigmatisation. They explained altogether about 43% of the total variability of predisposition to enact stigmatisation.

The interesting point is that adding the responses of those with high SD scores corrupted the extraction of factors on enacted stigmatisation making most factors unreliable. This supports the idea that responses of those with high social desirability scores could seriously corrupt the results of surveys on enacted stigmatisation and affect the validity of any questionnaire administered without such a scale.

The three factors selected by principal component analysis followed by varimax rotation which stood tests of reliability analysis revealed basic attitudes linked to origins of stigmatisation. These factors confirmed that these underlying origins included psychological, economic and genetic domains. Table 7.6 shows the main items in each factor, the loadings of each question on varimax, Corrected Item-total Correlation for each question, the reliability coefficient, Cronbach Alpha, for each factor and the figure for Cronbach Alpha if any particular question is removed from the factor.
<table>
<thead>
<tr>
<th>Questionnaire Items</th>
<th>Emotional Exclusion</th>
<th>Transaction Exclusion</th>
<th>Exclusion Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Would most people be happy to sit next to this man on a bus?</td>
<td>0.702</td>
<td>0.276</td>
<td>5.08E-02</td>
</tr>
<tr>
<td>2. Would most people be happy to eat food which he has cooked?</td>
<td>0.657</td>
<td>0.248</td>
<td>0.153</td>
</tr>
<tr>
<td>3. Would most people be happy to work in the mental hospital he and other people with similar problems are treated?</td>
<td>0.639</td>
<td>4.417E-02</td>
<td>-0.137</td>
</tr>
<tr>
<td>4. Would most people avoid talking to him if possible?</td>
<td>0.589</td>
<td>0.229</td>
<td>0.279</td>
</tr>
<tr>
<td>5. Would most people think he will be able to return to a completely normal life?</td>
<td>0.576</td>
<td>0.301</td>
<td>9.84E-02</td>
</tr>
<tr>
<td>6. Would most people think this man is a bad person?</td>
<td>0.532</td>
<td>0.124</td>
<td>0.516</td>
</tr>
<tr>
<td>7. Would most people think he should stay in hospital for his whole life?</td>
<td>0.516</td>
<td>0.214</td>
<td>0.379</td>
</tr>
<tr>
<td>8. If social services open a day centre for people like him in their neighbourhood, would most people have any objection?</td>
<td>0.349</td>
<td>0.260</td>
<td>0.264</td>
</tr>
<tr>
<td>9. Would most people be happy if this person became the teacher of their children?</td>
<td>0.112</td>
<td>0.793</td>
<td>0.116</td>
</tr>
<tr>
<td>10. Would most people be happy if he married their sister?</td>
<td>0.169</td>
<td>0.775</td>
<td>6.426E-02</td>
</tr>
<tr>
<td>11. Would most people be happy if he were to work together with them in their workplace?</td>
<td>0.326</td>
<td>0.675</td>
<td>8.411E-03</td>
</tr>
<tr>
<td>12. Would most people be frightened if this man came to live next door to them?</td>
<td>0.412</td>
<td>0.524</td>
<td>3.269E-02</td>
</tr>
<tr>
<td>13. Would most people think that he should take part in the making of important family decisions?</td>
<td>0.434</td>
<td>0.498</td>
<td>2.898E-02</td>
</tr>
<tr>
<td>14. Would most people think he is very likely to become physically violent?</td>
<td>0.421</td>
<td>0.431</td>
<td>0.233</td>
</tr>
<tr>
<td>15. If he is married, do most people think that, because of his condition, the law should allow his wife to divorce him without his consent?</td>
<td>0.213</td>
<td>0.415</td>
<td>0.382</td>
</tr>
<tr>
<td>16. Do most people think one of the main causes of his condition is a lack of moral strength or will power?</td>
<td>-4.197E-03</td>
<td>-2.843E-02</td>
<td>0.767</td>
</tr>
<tr>
<td>17. Do most people think his condition is a punishment for bad deeds?</td>
<td>0.112</td>
<td>-1.697E-02</td>
<td>0.735</td>
</tr>
<tr>
<td>18. Do most people think he has developed his condition to avoid the difficult problems of everyday life?</td>
<td>6.884E-03</td>
<td>2.489E-02</td>
<td>0.693</td>
</tr>
<tr>
<td>19. Do most people think he has become a failure in his life?</td>
<td>0.113</td>
<td>0.312</td>
<td>0.621</td>
</tr>
<tr>
<td>20. Do most people think he should be allowed to vote?</td>
<td>0.343</td>
<td>0.362</td>
<td>0.459</td>
</tr>
</tbody>
</table>

Table 7.6 bis. Loading figures for all the twenty questions in the questionnaire assessing perception of social stigmatisation, extracted by principal component analysis and subjected to varimax rotation. Note that of items with a loading of ≥0.500, the ones in bold type stood the test reliability analysis using Cronbach Alpha and so were included in the corresponding factor. E represents the figure 10 as the factor for the following figure which is the exponent.
<table>
<thead>
<tr>
<th>Questionnaire Items</th>
<th>Emotional Exclusion</th>
<th>Transaction Exclusion</th>
<th>Exclusion Justification</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Would you be happy if he married their sister?</td>
<td>0.144</td>
<td>0.709</td>
<td>5.999E-02</td>
</tr>
<tr>
<td>2. Would you be happy if this person became the teacher of their children?</td>
<td>0.172</td>
<td>0.704</td>
<td>1.717E-02</td>
</tr>
<tr>
<td>3. Would you think he is very likely to become physically violent?</td>
<td>-4.819E-02</td>
<td>0.684</td>
<td>0.118</td>
</tr>
<tr>
<td>4. Would you be happy if he were to work together with them in their workplace?</td>
<td>0.308</td>
<td>0.654</td>
<td>4.849E-02</td>
</tr>
<tr>
<td>5. Would you be frightened if this man came to live next door to them?</td>
<td>0.238</td>
<td>0.585</td>
<td>-0.145</td>
</tr>
<tr>
<td>6. Would you be happy to work in the mental hospital he and other people with similar problems are treated?</td>
<td>0.770</td>
<td>-2.400E-03</td>
<td>3.267E-02</td>
</tr>
<tr>
<td>7. Would you be happy to sit next to this man on a bus?</td>
<td>0.698</td>
<td>0.305</td>
<td>4.573E-02</td>
</tr>
<tr>
<td>8. Would you think he should stay in hospital for his whole life?</td>
<td>0.506</td>
<td>0.195</td>
<td>0.150</td>
</tr>
<tr>
<td>9. Would you be happy to eat food which he has cooked?</td>
<td>0.449</td>
<td>0.374</td>
<td>9.129E-02</td>
</tr>
<tr>
<td>10. Would you avoid talking to him if possible?</td>
<td>0.405</td>
<td>0.401</td>
<td>0.324</td>
</tr>
<tr>
<td>11. Would you think that he should take part in the making of important family decisions?</td>
<td>0.397</td>
<td>0.330</td>
<td>-2.766E-02</td>
</tr>
<tr>
<td>12. Do you think his condition is a punishment for bad deeds?</td>
<td>-4.156E-02</td>
<td>-4.263E-02</td>
<td>0.294</td>
</tr>
<tr>
<td>13. If social services open a day centre for people like him in their neighbourhood, would you have any objection?</td>
<td>0.251</td>
<td>0.195</td>
<td>-9.158E-02</td>
</tr>
<tr>
<td>14. Do you think he has become a failure in his life?</td>
<td>0.128</td>
<td>-5.371E-02</td>
<td>0.284</td>
</tr>
<tr>
<td>15. Do you think he has developed his condition to avoid the difficult problems of everyday life?</td>
<td>6.745E-02</td>
<td>9.003E-02</td>
<td>0.803</td>
</tr>
<tr>
<td>16. Do you think one of the main causes of his condition is a lack of moral strength or will power?</td>
<td>0.144</td>
<td>-5.017E-02</td>
<td>0.736</td>
</tr>
<tr>
<td>17. Would you think this man is a bad person?</td>
<td>-0.144</td>
<td>0.157</td>
<td>0.458</td>
</tr>
<tr>
<td>18. If he is married, do you think that, because of his condition, the law should allow his wife to divorce him without his consent?</td>
<td>2.706E-02</td>
<td>0.157</td>
<td>2.861E-02</td>
</tr>
<tr>
<td>19. Do you think he should be allowed to vote?</td>
<td>0.369</td>
<td>0.142</td>
<td>0.277</td>
</tr>
<tr>
<td>20. Would you think he will be able to return to a completely normal life?</td>
<td>0.184</td>
<td>0.359</td>
<td>-9.522E-02</td>
</tr>
</tbody>
</table>

Table 7.7 bis: Loading figures for all the twenty questions in the questionnaire assessing predisposition to enact stigmatisation, extracted by principal component analysis and subjected to varimax rotation. Note that of items with a loading of ≥0.500, the ones in bold type stood the test reliability analysis using Cronbach Alpha and so were included in the corresponding factor. Some loadings of less than 0.500 which stood tests of reliability were included in two of the final factors extracted in order to allow those factors to be comparable to the corresponding factors in perception of stigmatisation. E represents 10 as the exponent for the following figure which is the factor.
<table>
<thead>
<tr>
<th>Factor</th>
<th>Questions</th>
<th>Loading</th>
<th>Corrected Item-Total Correlation</th>
<th>Alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Exclusion <em>(psychological distancing)</em></td>
<td>Would most people be happy to sit next to this man on a bus?</td>
<td>0.702</td>
<td>0.5587</td>
<td>0.6747</td>
</tr>
<tr>
<td>Cronbach Alpha <em>(Reliability Coefficient) = 0.7439</em></td>
<td>Would most people be happy to eat food which he has cooked?</td>
<td>0.657</td>
<td>0.5457</td>
<td>0.6812</td>
</tr>
<tr>
<td>% of variance = 32.73</td>
<td>Would most people avoid talking to him if possible?</td>
<td>0.589</td>
<td>0.5712</td>
<td>0.6657</td>
</tr>
<tr>
<td></td>
<td>Would most people think he should stay in hospital for his whole life?</td>
<td>0.516</td>
<td>0.4825</td>
<td>0.7204</td>
</tr>
<tr>
<td>Transaction Exclusion <em>(Genetic; territorial; economic)</em></td>
<td>Would most people be happy if this person became the teacher of their children?</td>
<td>0.793</td>
<td>0.5944</td>
<td>0.6886</td>
</tr>
<tr>
<td>Alpha = 0.7627</td>
<td>Would most people be happy if he married their sister?</td>
<td>0.775</td>
<td>0.6014</td>
<td>0.6852</td>
</tr>
<tr>
<td>% of variance = 10.71</td>
<td>Would most people be happy if he were to work together with them in their workplace?</td>
<td>0.675</td>
<td>0.5751</td>
<td>0.7004</td>
</tr>
<tr>
<td></td>
<td>Would most people be frightened if this man came to live next door to them?</td>
<td>0.524</td>
<td>0.4823</td>
<td>0.7514</td>
</tr>
<tr>
<td>Allocation of Agency to an Internal Locus of Control in Patients <em>(Exclusion justification)</em></td>
<td>Do most people think one of the main causes of his condition is a lack of moral strength or will power?</td>
<td>0.767</td>
<td>0.5709</td>
<td>0.6903</td>
</tr>
<tr>
<td>Alpha = 0.7534</td>
<td>Do most people think his condition is a punishment for bad deeds?</td>
<td>0.735</td>
<td>0.5458</td>
<td>0.7008</td>
</tr>
<tr>
<td>% of variance = 5.52</td>
<td>Do most people think he has developed his condition to avoid the difficult problems of everyday life?</td>
<td>0.693</td>
<td>0.4817</td>
<td>0.7230</td>
</tr>
<tr>
<td></td>
<td>Do most people think he has become a failure in his life?</td>
<td>0.621</td>
<td>0.5290</td>
<td>0.7069</td>
</tr>
<tr>
<td></td>
<td>Would most people think this man is a bad person?</td>
<td>0.516</td>
<td>0.4733</td>
<td>0.7254</td>
</tr>
</tbody>
</table>

Table 7.6 Factors underlying perception of social stigmatisation extracted by principal component factor analysis and subjected to varimax rotation. All items in the three factors have loadings of higher than 0.500. One third of variability in perception of stigmatisation by its targets is explained by Emotional Exclusion. The factors extracted are likely to be linked to fundamental motives and origins of stigmatisation.
Looking at table 7.6, what is interesting is that at least one third of the total variability in the perception of stigmatisation by its targets is explained by *emotional exclusion*. In other words, what constitutes the greatest variability in the participants’ perception of social stigmatisation is not their being refused a job or marriage (as most are) but their being emotionally excluded — when others do not sit next to them, do not talk to them, do not think they are normal enough for friendship and association or think they should stay in mental hospital for the rest of their lives. This means that participants respond more unanimously to questions on their *perception of patients’ exclusion from transactions* or *perception of allocation of agency to patients* but there are more variability in responses to questions on *perception of patients’ emotional exclusion*.

Table 7.7 shows the results of factor analysis for questions assessing predisposition to enact stigmatisation. From the table, it is clear that all the loadings in *transaction exclusion* factor are high enough. In the *emotional exclusion* and the *allocation of agency* factors the loadings are the highest extracted by factor analysis which were retainable on reliability analysis. Among these were items with relatively lower loadings (< 0.500) which were retained for the purpose of comparability with the equivalent factors with the same items in perceived stigmatisation (Table 7.6). Yet as these low loadings could introduce undue approximation, it was decided to calculate total factor scores not by simply summing up the scores of the items with high loadings but by using the total score of any factor in both perceived and enacted stigmatisation areas. This led to the computation of standardised regression scores which were used, in linear regression, as variables to discover sociodemographic predictors of the attitudes underlying each factor.
<table>
<thead>
<tr>
<th>Factor</th>
<th>Questions</th>
<th>Loading</th>
<th>Corrected Item-Total Correlation</th>
<th>Alpha if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transaction Exclusion (Economic, Genetic, Territorial)</td>
<td>Would you be happy if he married your sister?</td>
<td>0.709</td>
<td>0.6156</td>
<td>0.6606</td>
</tr>
<tr>
<td></td>
<td>Would you be happy if this person became the teacher of your children?</td>
<td>0.704</td>
<td>0.5642</td>
<td>0.6901</td>
</tr>
<tr>
<td></td>
<td>Would you be happy if he were to work together with you in your workplace?</td>
<td>0.654</td>
<td>0.5110</td>
<td>0.7183</td>
</tr>
<tr>
<td></td>
<td>Would you be frightened if this man came to live next door to you?</td>
<td>0.585</td>
<td>0.5158</td>
<td>0.7179</td>
</tr>
<tr>
<td>Cronbach Alpha = 0.7544</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of variance = 27.06</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional Exclusion (Psychological distancing)</td>
<td>Would you be happy to sit next to this man on a bus?</td>
<td>0.698</td>
<td>0.5794</td>
<td>0.5764</td>
</tr>
<tr>
<td></td>
<td>Do you think he should stay in hospital for his whole life?</td>
<td>0.506</td>
<td>0.4627</td>
<td>0.6528</td>
</tr>
<tr>
<td></td>
<td>Would you be happy to eat food which he has cooked?</td>
<td>0.449</td>
<td>0.5087</td>
<td>0.6169</td>
</tr>
<tr>
<td></td>
<td>Would you avoid talking to him if possible?</td>
<td>0.405</td>
<td>0.4197</td>
<td>0.6816</td>
</tr>
<tr>
<td>Alpha=0.6967</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of variance = 10.36</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allocation of Agency to an Internal Locus of Control in Patients</td>
<td>Do you think he has developed his condition to avoid the difficult problems of everyday life?</td>
<td>0.803</td>
<td>0.4026</td>
<td>0.6573</td>
</tr>
<tr>
<td></td>
<td>Do you think one of the main causes of his condition is a lack of moral strength or will power?</td>
<td>0.736</td>
<td>0.5132</td>
<td>0.6024</td>
</tr>
<tr>
<td></td>
<td>Do you think this man is a bad person?</td>
<td>0.458</td>
<td>0.4251</td>
<td>0.6499</td>
</tr>
<tr>
<td></td>
<td>Do you think his condition is a punishment for bad deeds?</td>
<td>0.294</td>
<td>0.4490</td>
<td>0.6384</td>
</tr>
<tr>
<td></td>
<td>Do you think he has become a failure in his life?</td>
<td>0.284</td>
<td>0.4596</td>
<td>0.6296</td>
</tr>
<tr>
<td>Alpha= 0.6865</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of variance = 5.71</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 7.7 Factors underlying patients' & relatives' predisposition to stigmatise patients, extracted by principal component analysis and subjected to varimax rotation. Nearly 30% of the variability of predisposition to enact stigmatisation is explained by transaction exclusion (Economic, Genetic, Territorial) attitude.
Thirteen out of the twenty questions (65%) assessing perception of social stigmatisation were derived within the three factors extracted which suggests their construct validity (Rodeghier, 1996). These are questions that are recommended for use in future studies both as they are valid and because the number of original items may be excessive for use in community surveys. The thirteen items constitute the final form of the questionnaire for assessing perception of stigmatisation. The same questions the great majority of which have high loadings, plus four social desirability items derived following cross-validation (17 questions in total) constitute the final version of the questionnaire measuring the tendency to enact stigmatisation. The two questions with loadings of about 0.290 should be maintained in the latter to facilitate comparison between perceived stigmatisation and the tendency to enact stigmatisation (see Appendix III, A & B).

Fifty five per cent of relatives and 65% of patients obtained raw scores above a midpoint of 10 on perception of allocation of agency compared with 15% of relatives and 32% of patients on enactment of allocation of agency. Also, as noted above, loadings on factor analysis for some items of enacted allocation of agency for patients and relatives were rather low. This is likely to be the result of a defensive mechanism in the participants in that in response to questions such as “Do you think this man is a bad person?” they are passing judgment on themselves or their relatives. This does not necessarily mean that patients and relatives do not use exclusion justification as a factor of stigmatisation, rather outside their possible tendency to stigmatise less they may have difficulty in declaring justifications they use for stigmatisation that can easily apply to themselves.
CHAPTER VIII

LINEAR REGRESSION OF FACTOR SCORES AND
SOCIODEMOGRAPHIC VARIABLES
8.1 **Linear Regression**

Here, it is important to delve to some extent into the meaning and statistical concepts underlying linear regression as this technique is used extensively in this piece of research to discover the relationship between sociodemographic factors and stigmatisation scores for patients and relatives.

Linear regression is a statistical technique which determines, for example, which independent variable(s) (sociodemographic factors) within a given model can predict the value of a dependent variable (stigmatisation score). It also determines how much of the variability of the dependent variable is determined by the single or combined effect(s) of the independent variables in the model. The advantage of this technique is that it can measure the unique effect of a given independent variable within a given model while keeping the effect of other independent variables under control. A low significance level for the model allows one to reject the null hypothesis that there is no linear relationship between the dependent and independent variables (or that the independent variable(s) in the regression model is (are) not significant predictors of the dependent variable). Linear regression is devised essentially for quantitative variables but dichotomous variables which have Yes/No answers (such as black, non-black) could be given values of 0 to 1 and used as dummy variables just as quantitative variables.

In a regression computation (Table 8.1) **Constant** is the value of the dependent variable when all the independent variables are equal 0. **R** is the correlation coefficient between a given independent variable and the dependent variable. **R**\(^2\) is the proportion of total variability of the dependent

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variable explained by the independent variable. Residuals are the differences between observed and predicted values of the dependent variable. B is the partial correlation coefficient, i.e., the amount of change in the dependent variable for a one unit change in an independent variable and here for the change from 0 to 1 for a dummy variable (see below). For example, the partial correlation coefficient for female gender in a dummy system corresponds to the amount by which the stigmatisation score (dependent variable) will change for example for a female (1) compared with a male (0).

F is the ratio of the variability (variance) of the dependent variable explained by the regression model to the variability of the residuals (not explained by the regression model). Both variances are calculated as a total (Sum of Squares) and then divided by the degrees of freedom (number of cases minus one) to obtain a Mean Square (a measure of average variance). If F is high enough then the portion of the dependent variable that the regression model can predict outweighs the portion it cannot predict. If the ratio is close to 1, the null hypothesis that the independent variable(s) in the regression model is (are) not significant predictors of the dependent variable, is likely to be true. The significance level is the probability of getting a given F ratio if the null hypothesis is correct. This probability is obtained from comparing the value of F ratio with an F distribution. The F distribution is build on the basis of ratio of variances from random samples from normal populations. The F distribution is indexed by values of the number of observations in each sample (represented by degrees of freedom).

The standard error of B is the standard deviation of all population samples’ B coefficients. One has to know the probability of having a B coefficient as large as the one obtained, if the effect of a one unit change in a given independent variable on the dependent variable is zero, i.e., if the
The independent variable has no predictive power for the dependent variable. The difference (B - 0) divided by its standard error gives a t score whose probability can be determined by comparing it with a t distribution, i.e., the distribution of differences between an (S) statistic in a sample and the population mean for that statistic (M) divided by the standard error. This would be the probability of having that B coefficient if the null hypothesis were true.

The values of B for different independent variables cannot be compared with each other as each are expressed in a different unit. They can be standardised (Beta coefficients) when all the independent variables are expressed in standardised (z score) forms. Beta coefficients can be used to compare the unique effect of different independent variables on the dependent variable within a given regression model.

Stepwise linear regression which is used in this study is a technique of entering and removing independent variables in the model one by one while evaluating the predictive quality of the whole model at each step until no independent variable is left.

8.2 Association of Sociodemographic Characteristics with Stigmatisation Scores

The sociodemographic factors used in this study included age (18-29, 30-49; 50 and above); gender; social class (class I & II, class III-V, ‘unemployed’ and ‘students’; the latter two for patients); level of education (up to A levels, higher education); marital status (single, married/cohabiting, divorced/widowed/separated); ethnicity (European, African, African-
Caribbean, Asian, other); place of birth (Europe, Africa, Asia, the West Indies, other); first language (English, other European, other languages) and participants’ stance on the diagnosis (accepted, rejected, unsure).

Tests of appropriateness of the linear regression were performed for all the models derived. These tests confirmed that various assumptions underlying linear regression were satisfied for all the models built up in this analysis (Norusis, 1999) (assumptions such as normal distribution of the data and reasonable equality of variance of distribution of the values of each dependent variable for all the values of the independent variables within each model).

8.2.1 Patients’ Perception of Stigmatisation

8.2.1.1 Patients’ perception of their emotional exclusion

Patients’ perception of their emotional exclusion was dependent on patients’ age. The middle-aged and older patients (30 and above) seemed to perceive more emotional exclusion than younger patients (18 to 29 years old) (Beta = 0.359, P = 0.001), (Table 8.1).

The effect of age explains about 13% of the total variability and should only be given proportionate weight in explaining differences in patients’ perception of emotional exclusion. This means that it is likely that other factors are involved which explain the rest of the variability (see below, Discussion).
Table 8.1 Regression model for the predictive effect of middle and older age (30 and above) v. younger age (18 to 29) on patients' perception of their emotional exclusion in society. The effect of age explains about 13% of the total variability of the patients' perception of emotional exclusion.

As a matter of illustration, there was a statistically significant difference between patients depending on their age, in their perception of people's reluctance to eat food that a patient has cooked. Middle aged and older patients had a higher mean rank of perception of emotional exclusion than younger patients (Table 8.2).
This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.

Would most people be happy to eat food which he has cooked?

Patients' Responses

<table>
<thead>
<tr>
<th>Age</th>
<th>N</th>
<th>Mean Rank</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 to 29</td>
<td>25</td>
<td>36.24</td>
<td>906.00</td>
</tr>
<tr>
<td>30 plus</td>
<td>66</td>
<td>49.70</td>
<td>3280.00</td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mann Whitney U = 581.00; Wilcoxon W = 906.00; Z = -2.314; P (2-tailed) = 0.021

Table 8.2 Patients' responses to the Likert question asking whether most people are happy to eat food that a patient has cooked. Middle aged and older patients perceive more reluctance in people to do so than younger patients.

a. A lower Mean Rank indicates a lower perception of the related emotional exclusion.

8.2.1.2 Patients’ perception of their exclusion from transactions

Stepwise linear regression revealed that patients’ first language being an European language (which in this study was mainly English) as opposed to other languages predicted an increase in patients’ perception of their exclusion from transactions (such as work, teaching, marriage and neighbourhood) (Beta = 0.300, P = 0.005) (Table 8.3).
Table 8.3  Regression model for the predictive power of an European language as a first language on patients' perception of their exclusion from transactions in society. This effect accounts for about 10% of the total variability in patients' perception of their exclusion from transactions.

As a matter of illustration, there was a statistically significant difference between patients in their perception of people's reluctance for their sister to marry a patient, based on their first language. Patients whose first language was European (mainly English) perceived more reluctance than those with a non-European language (Table 8.4).
This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.

Would most people be happy if he married their sister?

<table>
<thead>
<tr>
<th>Patients' First Language</th>
<th>N</th>
<th>Mean Rank of Stigmatisation</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>European</td>
<td>80</td>
<td>48.71</td>
<td>3897.00</td>
</tr>
<tr>
<td>Non-European</td>
<td>12</td>
<td>31.75</td>
<td>381.00</td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mann Whitney U = 303.000; Wilcoxon W = 381.000; 
Z = -2.238

P (2-tailed) = 0.025

Table 8.4 Patients' responses to the Likert question asking whether most people be happy if a patient married their sister. Patients whose first language was European (mostly English) perceived more social reluctance to do so than those patients whose first language was non-European.

a. A lower Mean Rank indicates a lower perception of the related transaction exclusion.

8.2.1.3 Patients' perception of society's allocation of agency to an internal locus of control

Stepwise linear regression revealed that those patients who were almost permanently 'unemployed' because of their illness had a significantly lower perception of society's allocation of agency to patients (Beta = -0.255, P = 0.017) (Table 8.5).
Table 8.5  Regression model for the predictive effect of patients' status as 'unemployed' on patients' perception of allocation of agency by society. The variable 'unemployed' explains about 6.5% of the total variability of the patients' perception of allocation of agency to patients by society.

As an illustration one can compare the mean rank of patients' perception of society's belief whether their illness is a punishment for bad deeds, in employed and 'unemployed' patients (Table 8.6).
This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.

Would most people think his condition a punishment for bad deeds?

<table>
<thead>
<tr>
<th>Patients’ Responses</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>N</th>
<th>Mean Rank of Stigmatisation*</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>44</td>
<td>45.08</td>
<td>1983.50</td>
</tr>
<tr>
<td>Unemployed</td>
<td>35</td>
<td>33.61</td>
<td>1176.50</td>
</tr>
</tbody>
</table>

Mann Whitney U = 546.500; Wilcoxon W = 1176.500; Z = -2.320

P (2-tailed) = 0.02

Table 8.6 A comparison of responses of employed and unemployed patients to the question whether most people think that patients’ condition is a punishment for bad deeds. The ‘unemployed’ patients perceived less allocation of agency to an internal locus of control in patients.

a. A lower Mean Rank indicates a lower perception of allocation of agency.

8.2.1.4 Patients’ perception of linguistic stigmatisation

Stepwise linear regression revealed that ‘unemployed’ status decreased perceived linguistic stigmatisation by the patients (Beta = -0.286, P = 0.007), (Table 8.7).
Table 8.7 Regression model for the predictive effect of ‘unemployed’ status on patients’ perception of linguistic stigmatisation. Designations such as ‘schizophrenic’ can elicit compensatory benefits moderating patients’ perception of linguistic stigmatisation. The effect of the unemployed status explains about 8% of the total variability.

As an illustration one can compare the mean rank of perception of linguistic stigmatisation for employed and unemployed patients in their responses to whether ‘schizophrenic’ is devaluing as a diagnosis (Table 8.8).
Is it devaluing to call someone 'schizophrenic'?

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>N</th>
<th>Mean Rank of Stigmatisation</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>44</td>
<td>44.50</td>
<td>1958.00</td>
</tr>
<tr>
<td>Unemployed</td>
<td>35</td>
<td>34.34</td>
<td>1202.00</td>
</tr>
</tbody>
</table>

Mann Whitney U = 572.000; Wilcoxon W = 1202.000; Z = -2.076

P (2-tailed) = 0.038

Table 8.8 A comparison of responses of employed and unemployed patients to the question "Is it devaluing to call someone 'schizophrenic' "?

a. A lower Mean Rank indicates a lower perception of linguistic stigmatisation.

Building up the regression model by stepwise addition a second model is obtained in which the fact of being from higher social classes as opposed to being of lower social classes, unemployed or student increased the perception of linguistic stigmatisation (Beta = 0.208, P < 0.05) (Table 8.9).
### ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>131.121</td>
<td>2</td>
<td>65.560</td>
<td>0.351</td>
<td>0.123</td>
<td>5.974</td>
<td>0.004</td>
</tr>
<tr>
<td>Residual</td>
<td>932.868</td>
<td>86</td>
<td>10.975</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1063.989</td>
<td>87</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Coefficients

<table>
<thead>
<tr>
<th></th>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>10.956</td>
<td>0.478</td>
<td></td>
<td>22.917</td>
</tr>
<tr>
<td>Unemployed</td>
<td>-1.723</td>
<td>0.723</td>
<td>-0.241</td>
<td>-2.320</td>
</tr>
<tr>
<td>Higher Social Classes</td>
<td>2.875</td>
<td>1.435</td>
<td>0.208</td>
<td>2.004</td>
</tr>
</tbody>
</table>

Table 8.9 Regression model for the predictive effects of patients' unemployed status and their social class on their perception of linguistic stigmatisation. The effect of higher social classes increases the multiple $R^2$ by only about 4 per cent. This means that on its own it can explain about 4 per cent of the total variability of perception of linguistic stigmatisation by the patients while the effect of the unemployed status explains about 8% of the total variability.

### 8.2.2 Patients’ Stigmatisation of other Patients

#### 8.2.2.1 Patients’ emotional exclusion of other patients

When patients’ score for the emotional exclusion of other patients was entered into stepwise linear
regression with sociodemographic factors, it was revealed that being separated, widowed or divorced (Beta = -0.285, P = 0.007) predicted a decrease in patients’ emotional exclusion of other patients (Table 8.10).

### ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>7.770</td>
<td>1</td>
<td>7.770</td>
<td>0.285</td>
<td>0.081</td>
<td>7.621</td>
<td>0.007</td>
</tr>
<tr>
<td>Residual</td>
<td>87.688</td>
<td>86</td>
<td>1.020</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>95.458</td>
<td>87</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Coefficients

<table>
<thead>
<tr>
<th></th>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>0.08739</td>
<td>0.126</td>
<td>0.669</td>
<td>0.506</td>
</tr>
<tr>
<td>Sep/Wid/Div</td>
<td>-0.667</td>
<td>0.242</td>
<td>-0.285</td>
<td>-2.761</td>
</tr>
</tbody>
</table>

Table 8.10 Regression model for the predictive effects of patients’ being separated, widowed or divorced on their emotional exclusion of other patients. The effect of being separated, widowed or divorced explains about 8% of the variability of patients’ emotional exclusion of other patients.

Building up the regression model for all patients by stepwise method, a second model is obtained in which the fact of patients being a student too becomes predictive of reduced emotional exclusion of other patients (Beta = -0.287, P = 0.007) (Table 8.11).
Table 8.11  Regression model for the reducing effects of patients' divorced marital status and their being a student on their emotional exclusion of other patients.

As a matter of illustration, there was a statistically significant difference between patients who were students and other patients in their willingness to sit next to another patient on a bus (Table 8.12).
This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.

Would you be happy to sit next to this man on a bus?

Patients' Responses

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>N</th>
<th>Mean Rank of Stigmatisation*</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Students</td>
<td>13</td>
<td>28.65</td>
<td>372.50</td>
</tr>
<tr>
<td>Other Patients</td>
<td>79</td>
<td>49.44</td>
<td>3905.50</td>
</tr>
</tbody>
</table>

Mann Whitney U = 281.500; Wilcoxon W = 372.500; Z = -2.867
P (2-tailed) = 0.004

Table 8.12 A comparison of responses of patients who were students and other patients to the question whether they were happy to sit next to another patient on a bus.

a. A lower Mean Rank indicates a lower tendency for the relevant emotional exclusion of patients.

Building up the regression model a step further showed that those patients who rejected their own diagnosis were more likely to emotionally exclude their fellow patients (Beta = 0.201, P = 0.043).

(Table 8.13).
ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean Square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>18.971</td>
<td>3</td>
<td>6.324</td>
<td>0.446</td>
<td>0.199</td>
<td>6.945</td>
<td>0.0005</td>
</tr>
<tr>
<td>Residual</td>
<td>76.487</td>
<td>84</td>
<td>0.911</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>95.458</td>
<td>87</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Coefficients

<table>
<thead>
<tr>
<th></th>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>0.126</td>
<td>0.148</td>
<td>0.857</td>
<td>0.394</td>
</tr>
<tr>
<td>Divorced</td>
<td>-0.827</td>
<td>0.236</td>
<td>-0.354</td>
<td>-3.499</td>
</tr>
<tr>
<td>Students</td>
<td>-0.858</td>
<td>0.297</td>
<td>-0.292</td>
<td>-2.893</td>
</tr>
<tr>
<td>Rejected the Diagnosis</td>
<td>0.470</td>
<td>0.229</td>
<td>0.201</td>
<td>2.056</td>
</tr>
</tbody>
</table>

Table 8.13 Regression model for the predictive effects of patients' divorced marital status; their being student and their having rejected the diagnosis of schizophrenia on their emotional exclusion of other patients. The overall effects of the three variables account for about 20% of the total variability of patients' emotional exclusion of other patients.

This means that, within this model, patients who rejected their own diagnosis were more likely to emotionally exclude other patients — to avoid sitting next to them, talk to them, share food with them or wanting them released from psychiatric hospitals.

A parallel model showed that single patients compared to other patients tended to exert more emotional exclusion of other patients (Beta = 0.280, P = 0.008) (Table 8.14).
The table below shows the ANOVA summary for the regression model. The model includes both regression and residual components. The total sum of squares is 95.458, with 7.493 attributed to the regression and 87.965 to the residual. The mean square for regression is 7.493, and the mean square for residual is 1.023. The model's R value is 0.0280, with R square of 0.078 and an F value of 7.326, leading to a significant result (Sig. = 0.008).

The coefficients table indicates that the constant has a standardized coefficient of 0.280, with a t-value of -2.707 and significance of 0.008. The single marital status variable has a standardized coefficient of 0.280, a t-value of 2.707, and significance of 0.008. This suggests a significant predictive effect of patients' single marital status on patients' emotional exclusion.

Re-running the regression model for only single male patients shows that this effect is more intense for this group of patients (Beta = 0.347; P = 0.005) (Table 8.15).

Table 8.14 Regression model for the predictive effect of patients' single marital status on patients' emotional exclusion of patients.
ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>7.957</td>
<td>1</td>
<td>7.957</td>
<td>0.347</td>
<td>0.120</td>
<td>8.357</td>
<td>0.005</td>
</tr>
<tr>
<td>Residual</td>
<td>58.075</td>
<td>61</td>
<td>0.952</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>66.032</td>
<td>62</td>
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</table>

Coefficients

<table>
<thead>
<tr>
<th></th>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>-0.635</td>
<td>0.237</td>
<td>-2.682</td>
<td>0.009</td>
</tr>
<tr>
<td>Single</td>
<td>0.801</td>
<td>0.277</td>
<td>0.347</td>
<td>2.891</td>
</tr>
</tbody>
</table>

Table 8.15 Regression model for the predictive effect of male patients' single marital status on their emotional exclusion of other patients.

The higher value of Beta (0.347 compared with 0.280) means that being single predicts a higher level of emotional exclusion of other patients by male patients than by patients in general (whether male or female). Also the percentage of variability in patients' emotional exclusion of other patients explained by single marital status increase from about 8% for all patients to 12% for male patients. Re-running the regression model for female patients does not show any predictive effect of being single on female patients' emotional exclusion of other patients. Therefore, the effect of patients' being single on emotional exclusion of other patients is restricted to male patients but as, in this sample, there are more male patients the effect of being single in general becomes predictive of increased emotional exclusion of patients by patients in the sample (whether male or female). One can summarise these findings by concluding that being a single male patient
predicts an increase in the emotional exclusion of other patients (Table 8.15).

8.2.2.2 Patients' exclusion of other patients from transactions

When patients' scores on exclusion of other patients from transactions (refusing to let them teach their children, work with them, live next door to them or marry a member of their family) was entered into stepwise linear regression with sociodemographic factors as independent variables, it was revealed that being separated, widowed or divorced exerted an independent effect (Beta = 0.241; P = 0.023) by increasing patients' exclusion of other patients. This means that in this sample though divorced patients tended less to exclude other patients emotionally, from the point of view of more serious transactions (such as marriage) they excluded them more than single or married patients (Table 8.16).
<table>
<thead>
<tr>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>5.105</td>
<td>1</td>
<td>5.105</td>
<td>0.241</td>
<td>0.058</td>
<td>5.321</td>
</tr>
<tr>
<td>Residual</td>
<td>82.496</td>
<td>86</td>
<td>0.959</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87.601</td>
<td>87</td>
<td></td>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Constant)</td>
<td>-0.336</td>
<td>0.122</td>
<td>-2.748</td>
</tr>
<tr>
<td>Sep/Wid/Div</td>
<td>0.541</td>
<td>.0234</td>
<td>0.241</td>
</tr>
</tbody>
</table>

Table 8.16 Regression model for the predictive effect of patients' being separated, widowed or divorced on their exclusion of other patients from mutual transactions. The effect of being separated, widowed or divorced explains about 6% of the variability in patients' exclusion of patients from transactions.

Stepwise linear regression provided a second model in which being born in Asia was revealed to have an independent effect by increasing patients' exclusion of other patients from transactions (Beta = 0.212, P = 0.042) (Table 8.17).
Table 8.17  Regression model for the predictive effects of patients' being 'separated, widowed or divorced' and 'being born in Asia' on patients' exclusion of other patients from mutual transactions. The combined effects of being separated, widowed or divorced and being born in Asia explains about 10% of the variability in patients' exclusion of patients from transactions.

There were only 5 out of the 87 patients who had been born in Asia and though the finding is significant for this sample, one needs to be cautious about any generalisation of this result to the population of patients with schizophrenia as a whole.
8.2.2.3 Patients’ allocation of agency to an internal locus of control in patients

When patients’ score on allocation of agency to an internal locus of control in patients was entered into stepwise linear regression with sociodemographic factors as independent variables, it was revealed that having higher education exerted an independent effect ($\beta = -0.216$, $P = 0.043$) by reducing patients’ allocation of agency to an internal locus in patients (Table 8.18).

### ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>4.784</td>
<td>1</td>
<td>4.784</td>
<td>0.216</td>
<td>0.047</td>
<td>4.223</td>
<td>0.043</td>
</tr>
<tr>
<td>Residual</td>
<td>97.419</td>
<td>86</td>
<td>1.133</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>102.203</td>
<td>87</td>
<td></td>
<td></td>
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### Coefficients

<table>
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<tr>
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<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
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<td>0.430</td>
<td>0.134</td>
<td>3.207</td>
<td>0.002</td>
</tr>
<tr>
<td>Higher Education</td>
<td>-0.517</td>
<td>-0.252</td>
<td>-2.055</td>
<td>0.043</td>
</tr>
</tbody>
</table>

Table 8.18 Regression model for the predictive effect of patients’ having higher education on their allocation of agency to an internal locus of control in patients. The effect of higher education explains about 5% of the variability in patients’ allocation of agency to an internal locus of control in patients.
As an illustration, patients with higher education differed statistically significantly from other patients in their responses to the question whether they thought one of the main causes of a patient's condition was a lack of moral strength or will power (Table 8.19).

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>N</th>
<th>Mean Rank of Stigmatisation</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher Education</td>
<td>25</td>
<td>36.30</td>
<td>3097.50</td>
</tr>
<tr>
<td>Up to A Levels</td>
<td>64</td>
<td>48.40</td>
<td>907.50</td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 8.19  A comparison of responses of patients with up to A level and those with higher education to the question whether one of the main causes of patients' condition was a lack of moral strength or will power.

a. A lower Mean Rank indicates a lower tendency to allocate agency to an internal locus of control in patients.

8.2.3  Relatives’ Perception of Stigmatisation

8.2.3.1  Relatives’ perceived emotional exclusion

Perceived Emotional Exclusion scores were entered into stepwise linear regression with sociodemographic factors as independent variables. It was revealed that being middle-aged (30-
49 years old) exerted an independent effect by increasing relatives’ perceived emotional exclusion of patients. This means that middle-aged relatives perceived more distancing in society towards patients including not talking, not sharing food, not sitting next to them and wanting them locked up forever in mental hospitals (Beta = 0.202; P = 0.024), (Table 8.20).

### ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>4.956</td>
<td>1</td>
<td>4.956</td>
<td>0.202</td>
<td>0.041</td>
<td>5.260</td>
<td>0.024</td>
</tr>
<tr>
<td>Residual</td>
<td>116.822</td>
<td>124</td>
<td>0.942</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>121.778</td>
<td>125</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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### Coefficients

<table>
<thead>
<tr>
<th></th>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>-0.0419</td>
<td>0.107</td>
<td>-0.393</td>
<td>0.695</td>
</tr>
<tr>
<td>Middle aged (30 - 49)</td>
<td>0.418</td>
<td>0.182</td>
<td>0.202</td>
<td>2.293</td>
</tr>
</tbody>
</table>

Table 8.20 Regression model for the predictive effects of relatives’ being middle-aged on their perception of emotional exclusion of patients. The independent effect of relatives being middle-aged explains about 4% of the total variability of perception of emotional exclusion by relatives.

8.2.3.2 Relatives’ perception of allocation of agency to patients

Stepwise linear regression revealed that being non-European predicted an increase in the
perception of allocation of agency by society to an internal locus of control in patients (Beta = 0.219, P = 0.014) (Table 8.21).

### ANOVA

<table>
<thead>
<tr>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>5.883</td>
<td>1</td>
<td>5.886</td>
<td>0.219</td>
<td>0.048</td>
<td>6.275</td>
</tr>
<tr>
<td>Residual</td>
<td>116.249</td>
<td>124</td>
<td>0.937</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>122.131</td>
<td>125</td>
<td></td>
<td></td>
<td></td>
<td></td>
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### Coefficients

<table>
<thead>
<tr>
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<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
</tr>
<tr>
<td>(Constant)</td>
<td>-0.304</td>
<td>0.103</td>
<td>-2.964</td>
</tr>
<tr>
<td>Non-European Ethnicity</td>
<td>0.474</td>
<td>0.189</td>
<td>0.219</td>
</tr>
</tbody>
</table>

Table 8.21 Regression model for the predictive effects of relatives being of an ethnicity other than European on relatives' perception of allocation of agency in society to patients. The effect of this variable explains about 4% of the total variability of perceived allocation of agency in society to patients.

This means that non-European relatives (black in the majority) compared with European relatives perceived, more acutely, social attitudes attempting to allocate the cause of the illness to internal factors in patients.

As an illustration one can compare relatives' perception of society's belief about whether the
illness is a punishment for bad deeds between relatives of different ethnicities (Table 8.22).

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>N</th>
<th>Mean Rank of Stigmatisation*</th>
</tr>
</thead>
<tbody>
<tr>
<td>European</td>
<td>60</td>
<td>59.86</td>
</tr>
<tr>
<td>Black</td>
<td>29</td>
<td>77.74</td>
</tr>
<tr>
<td>Asians</td>
<td>8</td>
<td>60.75</td>
</tr>
<tr>
<td>Total</td>
<td>127</td>
<td></td>
</tr>
</tbody>
</table>

Chi Square = 6.410; DF = 2, \( P = 0.041 \)

Table 8.22  A comparison of responses of relatives from different ethnicities to the question whether most people think that patients' condition is a punishment for bad deeds. Kruskal Wallis Test.

a. A higher Mean Rank indicates a higher perception of allocation of agency by the relatives.

8.2.4  Relatives' Stigmatisation of Patients

8.2.4.1  Relatives' exclusion of patients from transactions

Stepwise linear regression revealed that relatives born in Africa had a higher tendency to exclude other patients from transactions (Beta = 0.199, \( P = 0.025 \)). (Table 8.23).
Table 8.23 Regression model for the predictive effect of having been born in Africa on the relatives' exclusion of patients from transactions. This accounts for about 4% of the total variability of relatives' exclusion of patients from mutual transactions.

8.2.4.2 Relatives' allocation of agency to an internal locus of control in patients

Stepwise linear regression revealed that being non-European (Beta = 0.321, P < 0.0005) compared with European predicted an increase in relatives' tendency to allocate the illness to an internal locus of control in patients (Table 8.24).
Table 8.24  Regression model for the predictive effect of relatives’ being of an ethnicity other than European on their allocation of an internal locus of control to patients. This effect explains about 10% of the total variability of relatives’ allocation of agency to patients.

As an example, it is interesting to note that in response to the question ‘Do you think his condition is a punishment for bad deeds?’ African-Caribbean relatives had the highest mean rank in allocation of agency to an internal locus of control in patients (Table 8.25).
This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.

'Do you think his condition is a punishment for bad deeds?'

### Relatives' responses

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean Rank of Stigmatisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>European</td>
<td>90</td>
<td>59.42</td>
</tr>
<tr>
<td>African-Caribbeans</td>
<td>21</td>
<td>83.50</td>
</tr>
<tr>
<td>Africans</td>
<td>8</td>
<td>63.69</td>
</tr>
<tr>
<td>Asian</td>
<td>8</td>
<td>64.69</td>
</tr>
<tr>
<td>Total</td>
<td>127</td>
<td></td>
</tr>
</tbody>
</table>

Chi Square 22.003; DF = 3  \( P < 0.0005 \)

Table 8.25 A comparison of the responses of relatives from different ethnicities to the question whether patients' condition is a punishment for bad deeds. Kruskal Wallis Test.

a. A higher Mean Rank indicates a higher tendency to allocate agency to an internal locus of control in patients.

Also, in response to the question ‘Do you think one of the main causes of his condition is a lack of moral strength or will power?’ African-Caribbean relatives had a significantly higher stigmatising score than Europeans (Table 8.26).
This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.

'Do you think one of the main causes of his condition is a lack of moral strength or will power?'

<table>
<thead>
<tr>
<th>Relatives' Response</th>
<th>N</th>
<th>Mean Rank of Stigmatisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>European</td>
<td>90</td>
<td>57.17</td>
</tr>
<tr>
<td>African-Caribbeans</td>
<td>21</td>
<td>82.19</td>
</tr>
<tr>
<td>Africans</td>
<td>8</td>
<td>80.06</td>
</tr>
<tr>
<td>Asian</td>
<td>8</td>
<td>77.00</td>
</tr>
<tr>
<td>Total</td>
<td>127</td>
<td></td>
</tr>
</tbody>
</table>

Chi Square = 12.609; DF = 3  \( P < 0.006 \)

Table 8.26 A comparison of the responses of relatives from different ethnicities to the question whether one of the main causes of patients' condition is a lack of moral strength or will power.

Kruskal Wallis Test.

a. A higher Mean Rank indicates a higher tendency to allocate agency to an internal locus of control in patients.

A second model derived by stepwise linear regression revealed that relatives' higher education reduced their tendency to allocate agency to an internal locus of control in patients (Table 8.27).
### ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>14.260</td>
<td>2</td>
<td>7.130</td>
<td>0.374</td>
<td>0.140</td>
<td>10.001</td>
<td>0.0005</td>
</tr>
<tr>
<td>Residual</td>
<td>87.695</td>
<td>123</td>
<td>0.738</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>101.955</td>
<td>125</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Coefficients

<table>
<thead>
<tr>
<th></th>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>-0.248</td>
<td>0.104</td>
<td>-2.384</td>
<td>0.019</td>
</tr>
<tr>
<td>Non-European</td>
<td>0.648</td>
<td>0.165</td>
<td><strong>0.328</strong></td>
<td>3.921</td>
</tr>
<tr>
<td>Higher Education</td>
<td>-0.364</td>
<td>0.158</td>
<td><strong>-0.193</strong></td>
<td>-2.303</td>
</tr>
</tbody>
</table>

Table 8.27  Regression model for the predictive effect of relatives' being of an ethnicity other than European and having higher education on their allocation of an internal locus of control to patients. The combined effects of these two variables explains about 14% of the total variability of the relatives' allocation of agency to patients.

As a matter of illustration, in response to the question, ‘Do you think one of the main causes of his condition is a lack of moral strength or will power?’, those relatives with education up to A levels had a significantly higher stigmatising score than those relatives with higher education (Table 8.28).
This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a schizophrenic.

Do you think one of the main causes of his condition is a lack of moral strength or will power?

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>N</th>
<th>Mean Rank of Stigmatisation*</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Higher Education</td>
<td>45</td>
<td>55.42</td>
<td>2494.00</td>
</tr>
<tr>
<td>Up to A Levels</td>
<td>83</td>
<td>69.42</td>
<td>5762.00</td>
</tr>
<tr>
<td>Total</td>
<td>128</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mann Whitney U = 1459.00, Wilcoxon W = 2494.00; Z = -2.301, P (2-tailed) = 0.021

Table 8.28  A comparison of relatives' responses to a question about patients' moral strength and will power, based on the highest level of education achieved by the relatives.

a. A lower Mean Rank indicates a lower tendency to allocate agency to an internal locus of control in patients.

8.2.5  **Differences between Patients and Relatives**

8.2.5.1  **Perception of stigmatisation**

There was no statistically significant difference between patients and relatives in their perception of patients' emotional exclusion in society and in their own emotional exclusion of other patients. There were nevertheless, significant differences as far as perception of transaction exclusion (Levene test: P = 0.017; t test: t = -2.968, DF = 165.356, P = 0.003); perception of allocation of agency (Levene test: P = 0.754; t test = 3.013, DF = 218, P = 0.003), their own exclusion of patients from transactions (Levene test: P = 0.247; t test: t = -1.989, DF = 218, P < 0.05) and their own allocation of agency to other patients (Levene test: P = 0.056; t test: 3.378, DF = 218, \(P = 0.001\)) were concerned.
a) Perception of transaction exclusion

Stepwise linear regression on the population of patients and relatives (n = 220) revealed that being a relative predicted an increase in the perception of exclusion of patients from transactions in society (Beta = 0.192, P = 0.003) (Table 8.29).

### ANOVA

<table>
<thead>
<tr>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>7.470</td>
<td>1</td>
<td>7.470</td>
<td>0.192</td>
<td>0.037</td>
<td>8.094</td>
</tr>
<tr>
<td>Residual</td>
<td>195.664</td>
<td>212</td>
<td>0.923</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>203.135</td>
<td>213</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Coefficients

<table>
<thead>
<tr>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>-0.216</td>
<td>0.102</td>
<td>-1.108</td>
</tr>
<tr>
<td>Relatives</td>
<td>0.380</td>
<td>0.133</td>
<td>0.192</td>
</tr>
</tbody>
</table>

Table 8.29  Regression model for the predictive effect of being a relative on the perception of patients' exclusion from transactions in society. The 'relative' variable accounted for about 4% of the variability of participants' perception of transaction exclusion.

b) Perception of allocation of agency

Stepwise linear regression on the population of patients and relatives (n = 220) revealed that being
a patient predicted an increase in perception of allocation of agency (Beta = 0.199, P < 0.003).

(8.30).

### ANOVA

<table>
<thead>
<tr>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>8.599</td>
<td>1</td>
<td>8.599</td>
<td>0.199</td>
<td>0.040</td>
<td>8.757</td>
</tr>
<tr>
<td>Residual</td>
<td>208.186</td>
<td>212</td>
<td>0.982</td>
<td>0.199</td>
<td>0.040</td>
<td>8.757</td>
</tr>
<tr>
<td>Total</td>
<td>216.785</td>
<td>213</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Coefficients

<table>
<thead>
<tr>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>-0.165</td>
<td>0.088</td>
<td>-1.867</td>
</tr>
<tr>
<td>Patients</td>
<td>0.407</td>
<td>0.138</td>
<td>0.199</td>
</tr>
</tbody>
</table>

Table 8.30 Regression model for the predictive effect of being a patient on perception of society's allocation of agency to patients. The effect of the variable 'patient' accounted for about 4% of the total variability of the perception of society's allocation of agency to patients.

8.2.5.2 Stigmatisation of patients

a) Enacted transaction exclusion

Stepwise linear regression on the population of patients and relatives (n = 220) revealed that being a relative predicted an increase in the exclusion of patients from transactions (Beta = 0.146, P = 0.032). (8.31).
### ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>4.244</td>
<td>1</td>
<td>4.244</td>
<td>0.146</td>
<td>0.017</td>
<td>4.636</td>
<td>0.032</td>
</tr>
<tr>
<td>Residual</td>
<td>194.077</td>
<td>212</td>
<td>0.915</td>
<td></td>
<td>0.017</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>198.321</td>
<td>213</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Coefficients

<table>
<thead>
<tr>
<th></th>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficients</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>-0.189</td>
<td>0.102</td>
<td>-1.853</td>
<td>0.065</td>
</tr>
<tr>
<td>Relatives</td>
<td>0.286</td>
<td>0.133</td>
<td>0.146</td>
<td>2.153</td>
</tr>
</tbody>
</table>

Table 8.31  Regression model for the predictive effect of being a relative on exclusion of patients from transactions. The effect of being a relative accounts for about 2% of the total variability of the exclusion of patients from transactions.

b) Enacted allocation of agency

Stepwise linear regression on the population of patients and relatives (n = 220) revealed that being a patient predicted an increase in the allocation of agency to patients (Beta = 0.229, P = 0.001). (Table 8.32).
ANOVA

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>DF</th>
<th>Mean square</th>
<th>R</th>
<th>R Square</th>
<th>F</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>11.350</td>
<td>1</td>
<td>11.350</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residual</td>
<td>204.158</td>
<td>212</td>
<td>0.963</td>
<td>0.229</td>
<td>0.053</td>
<td>11.785</td>
<td>0.001</td>
</tr>
<tr>
<td>Total</td>
<td>215.507</td>
<td>213</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Coefficients

<table>
<thead>
<tr>
<th></th>
<th>Unstandardised Coefficients</th>
<th>Standardised Coefficient</th>
<th>t</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Std. Error</td>
<td>Beta</td>
<td></td>
</tr>
<tr>
<td>(Constant)</td>
<td>-0.185</td>
<td>0.087</td>
<td>-2.115</td>
<td>0.036</td>
</tr>
<tr>
<td>Patients</td>
<td>0.468</td>
<td>0.136</td>
<td>0.229</td>
<td>3.433</td>
</tr>
</tbody>
</table>

Table 8.32 Regression model for the predictive effect of being a patient on allocation of agency to an internal locus of control in patients. The effect of being a patient explains about 5% of the total variability of allocation of agency to an internal locus of control in patients.

8.3 Discussion

In a linear regression model, independent variables (sociodemographic factors) which have a statistically significant predictive power for the dependent variable (stigmatisation score) are not necessarily the latter’s cause. The association between the independent variable and the dependent variable is one of association rather than causality. Yet, an interpretation based on causality is not excluded though cannot be proved on the sole basis of the results.

Table 8.33 shows a summary of the predictive power of various sociodemographic variables for
different attitudes in patients and relatives and the percentages of total variability of each factor that a given variable explains. The B value within each model show the effect of change of an independent variable by one unit (e.g, from being female to male, 0 to 1) on the dependent variable (factor score). The beta values within each model show the standardised effect of change of each variable by one z score on a factor score. They are not to be compared between models as the value of beta depends on the other variables within each model as well.

Having knowledge of a given variable for a patient or relative, these results allow one to predict the effect that it could have on the stigmatising attitudes. Patients and relatives came mostly from two adjoining boroughs in Central London and might differ from a sample from rural areas for example. Nevertheless, though the sample was moderate in size (220 patients and relatives) adequate care had been taken in sampling and randomisation and it might be safe to generalise the results to populations of patients and relatives in, at least, the UK inner city areas. There is, of course, always the possibility that with a larger sample size or sampling from a different pool some of these predictive variables change into others but it is also likely that a good number of them remain still predictive.

Stigmatisation is likely to increase in poorer economic circumstances. South Camden & Islington are two of the most deprived areas in the country with a population of 250,000. All the their wards have a higher level of deprivation compared to average for England and Wales, the most deprived being those around King’s Cross with Jarman Scores of between 40 to 62 (scores above 0 show higher deprivation
<table>
<thead>
<tr>
<th>Patients</th>
<th>Relative</th>
</tr>
</thead>
<tbody>
<tr>
<td>variable</td>
<td>Beta</td>
</tr>
<tr>
<td>Perception of Patients’ Emotional Exclusion</td>
<td>Middle age or older 0.359 13%</td>
</tr>
<tr>
<td>Perception of patients’ exclusion from transactions</td>
<td>European Language 0.300 9%</td>
</tr>
<tr>
<td>Perception of Allocation of Agency to Patients</td>
<td>Unemployed -0.255 6.5%</td>
</tr>
<tr>
<td>Perception of Linguistic Stigmatisation</td>
<td>Unemployed -0.241 12%</td>
</tr>
<tr>
<td></td>
<td>Social Class I &amp; II 0.208</td>
</tr>
<tr>
<td>Emotional Exclusion of other patients</td>
<td>Sep/Wid/div -0.354 20%</td>
</tr>
<tr>
<td></td>
<td>Student -0.292</td>
</tr>
<tr>
<td></td>
<td>Diagnosis Rejected 0.201</td>
</tr>
<tr>
<td></td>
<td>Single 0.280 8%</td>
</tr>
<tr>
<td>Exclusion of other patients from Transaction</td>
<td>Sep/Wid/div 0.236 10%</td>
</tr>
<tr>
<td></td>
<td>Born in Asia 0.212 10%</td>
</tr>
<tr>
<td>Allocation of Agency to an internal locus of control in patients</td>
<td>Higher Education -0.216 5%</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 8.33 A summary of variables predicting an increase or decrease (depending on the beta’s sign) of the scores of different factors. The data in italics compare the effect of being a patient or relative on the factor scores when all participants (patients and relatives) are entered into the regression model. Beta’s are standardised coefficients representing the effect of the variable on the corresponding factor scores. \( R^2 \) is the percentage of the total variability of a given factor score explained by a given variable.
than the average for England and Wales and scores below 0 show greater affluence than the average). The unemployment rate in South Camden is 11.8% and in Islington 12.1% compared with 4.8% for Great Britain. About 6.3% of the households in South Camden and 4.8% in Islington are overcrowded compared to 2.1% for England and Wales. About 23.4% of children in South Camden and 30.2% in Islington live in families which have a single parent compared to 13.2% in England and Wales (Health Information Team, 1999). The above data indicate that, on the basis of deprivation indices only, the results of the survey may be an over-estimation of the average level of stigmatisation in the UK inner city areas.

Nevertheless, this survey did not include those patients who were more or less constantly ill or rootless and these are precisely people who are likely to attract more stigmatisation because of their presentation and deteriorated state. The latter could have led to an under-estimation of the level of stigmatisation. Further, one must acknowledge the fact that though a response rate of 70.8% for patients and 84% for relatives are a priori satisfactory, those people who refused to participate may also have been particularly subject to social stigmatisation and, for this reason, avoided participating in a survey which, by the mere fact of investigating stigmatisation, reified it still further. This also might have led to an under-estimation of perception of stigmatisation. Also, people at times tend to report how they or most people ought to behave rather than how they actually do. Some respondents in my survey mentioned that in their answers to questions on their perception of stigmatisation by ‘most people’ what they tended to consider was not always how most people actually behave but how they should behave. As such the measurement of the perception of social stigmatisation in the survey, though already relatively high, is likely to be an underestimate of the real degree and extent of stigmatisation perceived by respondents. Overall, these factors could have led to an under-estimation of the level of stigmatisation and to
exclusion justification) from participants’ responses to the questionnaires but the results of linear regression of the scores of different factors against sociodemographic variables also indicated that rather different sociodemographic variables were significant predictors of these different stigmatisation factors (Table 8.33). This confirms that stigmatisation is a multidimensional construct which is consistent with previous research (Cohen & Struening, 1962; Taylor & Dear, 1981).

This study indicated a high degree of perceived stigmatisation by patients or relatives. This is compatible with most previous studies on patients’ or relatives’ perception of stigmatisation. Cumming & Cumming (1965) reported that 41% of patients in their study perceived high levels of stigmatisation. Nuehring (1979) reported moderate level and Miller & Dawson (1965), Spiegel & Younger (1972) and Link et al (1989) high levels of perceived social stigmatisation in patients. The results are also compatible with those reported by Nuehring (1979) Thompson & Doll (1982) Wahl & Harman (1989) on high levels of perception of stigmatisation by relatives.

This study also confirmed that there is a tendency in patients to stigmatise their fellow patients. This is consistent with findings by Swanson & Spitzer (1970), Shurka (1983) and several other studies (Weinstein, 1983). Beyond these findings, this study showed that patients’ tendency to stigmatise other patients is significantly less than the stigmatisation they perceive from society.

This study did not confirm the finding by (Angermeyer et al, 1987) who report that patients’ perception of stigmatisation reduced with increasing age. On the contrary, it suggests that being middle-aged increased both patients’ and relatives’ perception of patients’ emotional exclusion. This could be explained by the fact that in Angermeyer’s study patients having a recurrence were
also included and as younger patients are more likely to have more severe acute episodes the influence of younger age on perception of exclusion might be partly produced by the symptoms of the illness.

Middle-aged and older patients’ (30 and above) higher perception of patients’ emotional exclusion than younger patients (18 to 29 years old) means that middle aged and older patients noticed more attempts to exclude them emotionally such as people not sitting next to them, not sharing food with them, not talking to them and wanting them in mental hospitals forever. This is compatible with the fact that most patients deteriorate with more recurrences as age goes by and so are subject to more stigmatisation. Middle-aged and especially older populations, even without schizophrenia, are more likely to undergo, more or less, some degree of isolation. Stigmatisation of schizophrenia comes to compound this problem of older populations of patients in that the latter find themselves secluded in either hospitals, hostels, prisons or roads with more experience of loneliness and more feelings of solitude and disconnectedness than younger patients. The above finding emphasises the importance of attention to the burden of emotional exclusion in middle-aged and older patients. By virtue of being younger and so less deteriorated, younger patients seem to be slightly less frequently the target of emotional exclusion yet this of course does not mean that they do not feel emotionally excluded. Middle-aged relatives too perceived more distancing in society towards patients. This may mean that middle-aged relatives may be more than younger relatives in touch with the emotional exclusion of patients because of their own familiarity with it as their age advances.

In general, being a patient, as opposed to being a relative, predicted an increase in perception and also allocation of agency to patients. This is likely to indicate a proportionately higher level of
social pressure by doctors, relatives, neighbours, friends, acquaintances, media and society in
general to allocate responsibility to patients, considering them as lacking moral strength or will
power, as a failure, a ‘bad person’ who has become ill in order to avoid the difficulties of everyday
life. It is likely that patients internalise the social pressure and subsequently apply these same
introjected images onto other patients more than their relatives do as the latter are less subjected
to such social pressure.

The perception of allocation of agency to patients is moderated when society officially
acknowledges patients’ exoneration from work with the implied message that they lack
responsibility and are innocent. Patients who were unemployed perceived a lower degree of
allocation of agency by society to patients. The medical model emphasises innocence and
entitlement to support by society for patients who, in this way, are considered as implicitly not
accountable for their illness. In this study, patients who were considered as ‘unemployed’ were
those who had either never worked or were permanently ‘off work’ because of repeated
recurrences. The status given them by society is likely to imply lack of at least direct responsibility
for the illness. It is therefore understandable why this particular group of patients should perceive
less allocation of agency to them by society.

The same group, compared to all other patients, also perceived less linguistic stigmatisation in
designations used to refer to patients as these designations are compensatory in the sense of
justifying material benefits and the ‘right’ to be off-work quasi permanently as an acknowledgment
of their lack of agency. So the unemployed group through their inclusion on social security lists
for more material benefits by virtue of the diagnosis are likely to perceive a lower degree of
linguistic stigmatisation in terms such as ‘schizophrenic’. The regression results also showed that
patients from higher social classes are likely to perceive more linguistic stigmatisation in these terms. This confirms previous conclusion made in chapter VI on the basis of the analysis of patients' discourse in the sense that higher social classes are likely to lose economically more by taking on stigmatising designations as the latter are more likely to jeopardise their existing status quo and economic position.

Non-European relatives (black in the majority) perceived more than European relatives social attitudes attempting to allocate the cause of the illness to internal factors in patients. This is in agreement with the cultural expectations of Africans and African-Caribbeans of the locus of agency to be located in patients. In the Caribbeans schizophrenia is not designated as such and is considered as a supernatural phenomenon produced, according to some explanatory models, by spirits or obeah (sorcery) with the locus of control located in the patient, such as being weak or having committed vice or taken drugs (Littlewood, 1988). My study suggests that at present African-Caribbean relatives in the West are likely to be maintaining their beliefs about the internal locus of control.

For a similar reason, non-European relatives themselves had a higher tendency to allocate an internal locus of control to patients. This is compatible with both older studies (Fournet, 1967) on black respondents in Louisiana and early results from a more recent study, Littlewood (1998), which suggest that African-Caribbeans in Trinidad (Port-of-Spain) stigmatise more than the white British.

This results also showed that having higher education exerted an independent effect by reducing patients’ and relatives’ allocation of agency to an internal locus in patients. As an illustration,
patients with higher education differed statistically significantly from other patients in their responses to the question whether they thought one of the main causes of a patient’s condition was a lack of moral strength or will power. The effect of years of education on reducing relatives’ allocation of agency to an internal locus of control in patients is compatible with previous data which reported significant relationships between relatives’ educational level and “enlightened attitudes” towards the aetiology of mental illness and whether patients are to be blamed for their condition (Freeman, 1961). There are also a range of other studies (Cumming & Cumming, 1957; Nunnally, 1961; Taylor & Dear, 1981; Brockington et al, 1993) which indicate that stereotyped images of mental illness are less pronounced among people with higher levels of education. None of these studies have focused on this particular stigmatisation factor, i.e., the allocation of agency to an internal locus of control in patients.

The survey suggested that patients’ first language being an European language (which in this study was mainly English) as opposed to other languages predicted an increase in patients’ perception of their exclusion from transactions (such as work, teaching, marriage and neighbourhood. This can just correspond to an association yet interpretations based on causality are not excluded. Is it the case that those whose first language is not European (mostly immigrants from the third world) are reporting part of their experience in another culture? This is not very likely as the place of birth had no predictive effect as an independent variable in the regression model for this sample. Alternatively, is it the fluency of respondents in at least one European language (mostly English) that makes them more ‘perceptive’ in responding to a questionnaire whose language is English? The latter is also unlikely because if it had been the case it would have also affected the scores for other factors such as perception of emotional exclusion and perception of allocation of agency which it does not. Yet, there remains another possibility. Is
it the case that a medium of communication such as an European language makes people more acutely aware of their rights, including rights to equal treatment in society? Or is there anything in the structure of English (and other European languages) as opposed to other patients’ first languages (Turkish, Arabic, Yoruba, Kalabari, Igbo, Twi, Tigrinya, Tamil, Kurdish, Gujarati etc.) that makes the perception of exclusion from transactions slightly more acute? The latter is conform with the Sapir-Whorf hypothesis on the effect of the structure of language on thought processes. Having said this, the most conservative interpretation is that in this sample an European first language (mainly English) predicted an increase in the patients’ perception of their exclusion from transactions.

Being a relative as opposed to being a patient predicted an increase in the perception of exclusion of patients from transactions in society. This is likely to indicate more observation of stigmatisation (and possibly activism of relatives in the sense of voicing their experiences of stigmatisation) compared with patients. Also, relatives are likely to have to face the consequences of stigmatisation not only that directed at patients but also that at themselves, for example in the form of refusal by members of the public to establish family relationship with them through marrying someone in their family. They are also more likely to be faced with neighbours’ protests at them for lodging the ill member of the family at home.

Patients’ being separated, widowed or divorced predicted a decrease in patients’ emotional exclusion of other patients. It is possible that divorced patients could empathise with other patients inasmuch as they recognise their emotional isolation more easily. It may also be partly explainable by the fact that divorced patients themselves are likely to be more emotionally isolated than other patients and more likely, for example, to wish to associate, sit next to, talk with or
share food with other patients yet the regression analysis also showed that divorced, separated and widowed patients are less willing to get involved with more serious transactions with other patients including marriage of someone in their family with a patient. Patients being student also predicted a decrease in patients' emotional exclusion of other patients. This may result from lower political and psychological conservatism in patients who are students. On the contrary, patients who rejected their own diagnosis were more likely to emotionally exclude other patients — to avoid sitting next to them, talk to them, share food with them or wanting them released from psychiatric hospitals.

One of the possible reasons why some patients tend to exclude fellow patients from friendship may be that they do not want to become or be seen as identified with them and therefore be equally stigmatised in different areas of social life. This may include losing their chances of finding a marital partner. Single patients with schizophrenia, especially males, usually have more difficulty finding a marital partner and a lot of them remain unmarried and childless. Also, they may be subject to more stigmatisation (Philips, 1964; Farina et al, 1973) as the stereotype of a ‘mad’ person seems to be traditionally associated with a male figure. For these reasons, single male patients are likely to exert more emotional exclusion on other patients in order to avoid being seen as “one of them.”

Being a relative predicted an increase in the exclusion of patients from transactions. This was true especially for relatives born in Africa. It is possible that relatives, confronted with transaction exclusion, that they perceive more acutely than patients, find themselves in a situation in which they have to stigmatise other patients in order to reduce stigmatisation directed at themselves. The patient’s sister marrying another patient means bringing in another target of social
stigmatisation into their circle. Having another patient as their neighbour means further isolation and avoidance of their neighbourhood by other people. Working with other patients or letting a patient teach their children means further association, propinquity, proximity and consequently more identification with other patients and their relatives. In a paradoxical turn of the situation, stigmatisation is used as a defence against stigmatisation.

As discussed previously, the relationship between a variable and intensity of stigmatisation is of course predictive rather than causal nevertheless a causal relationship is not totally excluded. Some of the possible causal links, for example, that between patients’ middle or older age and an increase in patients’ perception of emotional exclusion or that between patients’ being on material benefits or being exonerated from work and a decrease in patients’ perception of allocation of agency and perception of linguistic stigmatisation; or single status of male patients and an increase in the patients’ emotional exclusion of other patients were discussed above. These interpretations are plausible yet should be taken on with due caution.

Other variables determining patients and relatives’ tendency to stigmatise or perceive stigmatisation might include post-hospital patients’ symptoms and behaviours Freeman, 1961 on relatives’ tendency to stigmatise; Freeman & Simmons, 1961 and Phelan et al, 1998 on relatives’ perception of stigmatisation) relatives’ personality characteristics and type of kinship between patients and relatives (Freeman & Simmons, 1961), living apart from family, alone or with unrelated persons (Nuehring, 1979 on patients’ perception of stigmatisation; Phelan et al, 1998), recent episode of hospitalisation within the past six months (Phelan et al, 1998). In all these cases the percentages of variability explained by each of these variables turned out to be relatively low. Though this research did not quantify all these other variables, a qualitative exploration of specific
experiences of stigmatisation by patients and relatives was done by the analysis of their discourse.

In the case of patients and relatives, focusing interventions on participants from specific sociodemographic groups such as African-Caribbean relatives or single male patients is likely to be helpful yet one has to be aware of the facts that:

1) as mentioned above, there are other variables which explain a greater proportion of the total variability of stigmatisation in patients and relatives so blanket interventions covering a wide variety of patients and relatives might be necessary.

2) stigmatisation by patients and relatives are not just driven by the same motivations for stigmatisation in society at large but also as a reaction to stigmatisation by society per se. It is stigmatisation to avoid stigmatisation. For example, patients may have more reasons to avoid other patients for fear of becoming identified with them, categorised with them and stigmatised. This means that though anti-stigmatising interventions would be fruitful in patients and relatives, they have to go hand in hand with and even subsequent to anti-stigmatising interventions in society at large. So long as patients are sanctioned negatively by society they would have strong reasons to avoid being identified with other patients and find themselves in a situation in which, in order to protect themselves, they have to stigmatise. Entering into a friendly conversation in a public place with someone known as a ‘schizophrenic’ in the local community means being recognised as “one of them” and stigmatised. Therefore sometimes the ‘safest’ tactic might be for these patients to avoid the other patient in order not to reveal their association with them. This is likely to be more true for ethnic minorities who have to cope with an already heavy burden of stigmatisation due to their ethnic background and socioeconomic position.
An important feature of these results is that the percentages of the variability of stigmatisation, i.e., the magnitude of the relationship with stigmatisation that each variable explains is low to moderate (2 to 20%). This means that these variables have low predictive powers and limited practical utility. The finding is compatible with reports of previous studies both in patients (Nuehring, 1979) and the general public (Taylor et al, 1979; Sellick & Goodyear, 1985; Brockington et al, 1993). This indicates that the tendency to stigmatise is not so much a function of participants’ sociodemographic characteristics as the function of as yet unknown variables which determine the rest of participants’ variability in their replies to the questions on stigmatisation. So the essential question remains — what are the factors which explain the largest portion of variability in stigmatisers?

It is likely that one of the variables that explains most of the chunk of the variability in stigmatisation is probably differences in people’s tendency to pursue self-interest especially when the latter is not seriously threatened. As mentioned earlier, in both perceived stigmatisation and predisposition to enact stigmatisation, areas which attract a stigmatising response in the highest percentages of participants tend to have a high ‘self-interest value’ (physical safety, major transactions, genetic self-interest, etc). Higher percentages of participants respond to such questions in the scored (stigmatising) direction unanimously and this means that there is the lowest variability and the highest unanimity among participants in giving scored (stigmatising) responses when the issue has a high self-interest value (such as allowing one’s sister to marry someone with schizophrenia or letting the latter teach one’s children). As the self-interest value at issue in some questions becomes less serious, there appears to be more variability in responses based on individual differences in the extent of pursuit of self-interest. These variabilities are likely to depend on personality factors and cultural, political, religious and ideological values of
patients and relatives. Nevertheless, participants’ responses in the present state of civilisation as a whole, though showing differences in magnitude, tend to point to the same general direction and meaning: pursuit of self-interest. Consequently, while working towards a political ideological system which, it is hoped, will moderate the pursuit of self-interest, campaign messages which allay anxieties of the public about their safety and security (forums for expression of anxiety and fear) and heed their advantages and interest (by positive reinforcement of anti-stigmatising or non-stigmatising behaviours and initiatives) are more likely to be successful. Anti-stigmatising interventions taking place at a macro level such as economic, legislative, cultural and political interventions will be discussed further in the next chapter.
CHAPTER IX

ROUTES TO DE-STIGMATISATION
9.1 Introduction

De-stigmatisation is the agenda of the day. What are the motivations for this trend? Does it have as aim to soften the effects of us stigmatising others, i.e., our camouflaged ‘aggression’, and to moderate our own guilt? Is ‘aggression’ an inevitable part of us and benevolence inconceivable other than for moderating the effects of our ‘aggression’? Can the explanation for de-stigmatisation be that, through identification with the stigmatised, we protect ourselves against some susceptibility to stigmatisation on the grounds of our own stigmas? Is de-stigmatisation encouraged because, through protecting the ill and the weak, one promotes the group cohesion and the credibility of the state and those in power? Is de-stigmatisation a way of functionally integrating the stigmatised into the social system without them presenting any threat to the state and its domination? Is de-stigmatisation expropriation of the problem from those to whom it is claimed to pertain? If the conflict between stigmatisers on one hand and the stigmatised on the other is a conflict over resources, why do stigmatisers (and those in power) try to destigmatise? Does granting de-stigmatisation confirm the power of whoever grants it? Can one think it improbable that de-stigmatisation serves the benefits of stigmatisers as well as those of the stigmatised? So many possibilities but there remains still some other important ones: we de-stigmatise for philanthropic reasons, as part of a desire for freedom from all forms of oppression and as a wish to contribute to the spirit of historical progress.

9.2 The Structure of Stigmatisation

To develop a solid, reasoned and goal oriented anti-stigmatisation campaign one has to have clear
ideas about the structure of stigmatising attitude. The constructive validity of the affective, 
cognitive and behavioural components of attitudes has been clearly demonstrated by analysis of 
covariance (Bagozzi, 1978).

Stigmatisation generally implies prejudice, i.e., an unwarranted or disproportionate negative 
attitude with little or no consideration of people’s individuality, which like any other attitude has 
three components: cognitive (attributed stigmatisation), affective (a range of negative feelings 
such as fear, hate, pity and contempt) and behavioural (discrimination, segregation, addressing 
someone as ‘mental’ or ‘schizophrenic’ or subtle acts such as walking away, turning one’s head 
aside, sitting apart, snubbing, not smiling). Research indicates that, with certain exception (Lee 
& Ottati, 1993), we tend to have more homogeneous, generalizing or stereotypic ideas about 
members of groups outside our own group (out-groups) than about members of our own group 
(in-group) (Linville & Jones, 1980; Judd et al, 1991). This is partly because we know members 
of our own group better individually and it might not be possible or cost-effective to attempt to 
know all members of an out-group just to be individually ‘fair’ on them. By having a gross 
generalising idea about members of a certain group, accuracy or fairness is sacrificed for the 
possible self-protection that the knowledge might offer.

In brief, like all attitudes, the stigmatising attitude has three components: cognitive: “schizophrenics are violent”, affective, e.g., anxiety, and discrimination, e.g., “I won’t give them 
accommodation.” If and when discrimination is exercised, and depending on the stigmatiser’s 
personality, situational variables and other attitudes, e.g. “I am against prejudice”, stigmatisers 
are likely to feel some degree of discomfort coming from the discrepancy between their 
stigmatising attitude and their other attitudes (Monteith, 1996) and in order to reduce the resulting
cognitive dissonance (Festinger, 1957) they are likely to either moderate their stigmatising attitude, eliminate the awareness of the stigmatising attitude by seeking out information supporting their stereotype (Skov & Sherman, 1986; Pendry & McRae, 1994), or deny or trivialise their attitude (Simon et al, 1995) — “I stigmatise no one.”

9.3 Targets in Anti-stigmatisation Campaigns

Based on the structure of the stigmatising attitude one could explore possible levels of intervention in anti-stigmatisation campaigns:

1) The cognitive level of stigmatising attitude ⇒ Educational Intervention
2) The affective level of stigmatising attitude ⇒ Psychological Intervention
3) The discrimination level of stigmatising attitude ⇒ Legislative Intervention
4) The economic level of stigmatising attitude ⇒ Political Intervention
5) The denial level of stigmatising attitude ⇒ Linguistic Intervention
6) The evolutionary level of stigmatising attitude ⇒ Intellectual and Cultural Intervention

As these intervention tend to target a fundamental human tendency they are, by nature, provocative and challenging. Some of them such as legislative, linguistic, political, intellectual and cultural interventions would incite controversies, struggles and debates but these are precisely what are required as catalysts for change and social development. The value of a social theory is not for it to be necessarily true but for it to create such atmosphere in which new discoveries are made.
9.3.1 Educational Intervention

9.3.1.1 Enhanced social desirability induced by campaigns of public education

Trying to change attitudes towards patients with mental illness, some authors found public education to be ineffective (e.g., Cumming & Cumming, 1957; Gatherer & Reid, 1963; Domino, 1983; Wahl & Lefkowitz, 1989) while others reported some effect (e.g., Morrison et al, 1979; Keane, 1991; Penn et al, 1994; Thornton & Wahl, 1996; Wolff et al, 1996a). All these studies are bedevilled by an error one could describe as the effect of Enhanced Social Desirability (ESD). Nunnally (1961) discovered that people were likely to show as much improvement on repeat administration of an attitudinal questionnaire with or without any intervening course or education. He was puzzled and expressed surprise at his findings yet he did not give any explanation why it should be so. It appears now that campaigns of public education are likely to enhance the effect of social desirability factor on people's responses in post-campaign surveys, compared with the same effect on their responses in pre-campaign surveys, even for people not exposed to the campaign material, by the mere fact that during the campaign people are given implicit messages about the objectionability of stigmatisation in so many ways. As such whatever social desirability was attached to people's answers to the questionnaires pre-campaign, is likely to be enhanced in post-campaign surveys as the very result of the tacit message 'It's not appropriate to stigmatise' communicated to the public in so many ways during the campaign itself. The ESD is likely to be subsequently interpreted as 'improvement in public attitudes through education'. If stigmatisation is uniquely biological, excluding any major cultural, economic and sociopolitical contributions,
why do we then organise anti-stigmatisation campaign? One can propose that it is possible to measure ESD by the difference between pre- and post-campaign lie scores but when it is not measured it is always necessary to entertain its likely effect on the data.

The results of large-scale campaigns of public education in Britain (Paykel, 1997, 1998) and those of the World Psychiatric Association's recent extensive programme of public education in Calgary, Canada (reported with permission from Norman Sartorius) suggest that large scale campaigns of education have had relatively little impact on public attitudes. The results of local targeted efforts concentrating on young people in Calgary schools have been more rewarding. Yet, there is no evidence how long the acquired shift in the local youth's attitudes might last especially that young people are going through transitional stages in which they are likely to empathise with new ideologies and identify with minorities in a world in which they themselves are questioning their position in comparison with older generations. There is no reason to believe that the acquired shift in attitudes will last as these young people reshape their identity, move further in their developmental stages of life, get married, have children and then would be placed in a population category who have stronger motivations to pursue self-interest and to stigmatise. They would then have to decide whether they want to live next door to someone who has schizophrenia.

9.3.1.2 Questionnaires measuring cognition rather than attitudes

What one measures by 'attitudinal' questionnaires are cognitive hypotheses by participants themselves of what they would think of, feel or do towards the general category of patients with
mental illness. As such the results of the surveys are neither a measure of behaviour nor a measure of feelings towards the larger group of patients and therefore not a measure of attitudes because as mentioned above, the latter have affective and sometimes behavioural components as well. The mind of a person subjected to a cognitive task such as a post-campaign pencil-and-paper survey is likely to function on a different level than when the same person is, in effect, subjected to the emotional stress of encountering a flesh-and-blood, disturbed patient. Extrapolating from social psychological studies (Stephan & Stephan, 1985; Dijker, 1987; Mackie et al, 1989; Wilder & Shapiro, 1989; Islam & Hewstone, 1993) which demonstrated that arousal increases the power of stereotypes and limits access to one’s cognitive reserves one could conclude that the anxiety and fear resulting from an actual encounter with an acutely ill patient are likely to disperse most of the cognitive effect of previous public education. Yet, cognitions do matter as the inevitable awareness of the stigmatised of the cognitive elements of the people’s attitudes put the former in a position in which they feel vulnerable to what others may choose to do whether in practice they do it or not.

9.3.1.3 People selecting information

The input that leads to a new emotional experience for the public is likely not to consist of telling them that patients are curable but of the public not hearing any more that someone with mental illness committed an act of violence. Development of cure for mental illness is likely to reduce stigmatisation not when the latter is just given as cognitive data but when the latter is shown. Any possible effects of public education is likely to burn out with time as people tend to actively seek out new information that confirm their pre-existing stereotypes (Skov & Sherman, 1986; Pendry
Further, though people with a better understanding of mental illness are self-reportedly less likely
to stigmatise (Link et al, 1987; Brockington et al, 1993) the correlation may be due to the fact
that those already less likely to stigmatise hold on to the information confirming their relatively
positive stereotypes rather than their knowledge making them less likely to stigmatise. The study
by Wolff et al (1996a) suggests that participants who showed negative attitudes at baseline were
likely to refuse to be re-interviewed post-campaign. This suggests that those who already had
negative attitudes probably preferred to hold on to their stereotype, repelling approach by those
carrying information potentially disconfirming it. This is in agreement with other findings by
O'Sullivan & Durso (1984) which suggest that information inconsistent with one’s stereotype is
likely to be refuted or denied. It is also consistent with what happens in campaigns for changing
attitudes towards minority groups (Devine, 1995) — the information ‘reaches’ those who already
‘agree’ with it. Also, the pressure involved in the counter-stereotypical messages given to people
in anti-stigmatisation protests (Macrae et al, 1996) might make people comply in surface with the
word of wisdom and suppress the stigmatising attitudes underneath. In such cases overt acts of
discrimination are either converted into subtler forms, or inhibited with the possibility of a
subsequent strong rebound effect (Macrae et al, 1994b).

9.3.1.4 Talking to the feelings rather than imparting information

To reduce discrimination, one has to reach people’s heart at the same time as their mind. The idea
that campaigns of de-stigmatisation could be run solely by educating the public circumvents the affective component of the stigmatising attitude. The stigmatiser, like almost anyone else, has involuntary unconditioned emotional responses (arousal, anxiety and fear) to certain events (serious accidents or death) and conditioned responses to whoever reminds them of these events (someone lacking sanity, a mutilated person, a terminally ill person). According to behavioural theory, people take steps to avoid negative events and so the stigmatiser is likely to avoid the stigmatised to get away from the instances of anxiety and fear that they cause in him (Berger & Luckmann, 1966; Schutz, 1971) and every new instance of avoidance reinforces the avoidance behaviour itself (negative reinforcement). Information alone is unlikely to demolish stigmatising attitudes as the latter are three-storey buildings of course with a cognitive level but two other floors as well (Fig. 2.1). Antistigmatisation is likely to need something deeper than logic. To lecture people that patients with mental illness are not dangerous and that people should not worry about them is like saying to someone who has flight phobia that the aeroplane is safe and that he should not hesitate boarding!

Research by an increasing number of investigators (e.g., Bodenhausen, 1993; Bodenhausen et al, 1994; Jussim et al, 1995) suggests that it is the feeling rather than the cognitive component of attitudes that determines people’s social judgment. Though some stigmatising attitudes are adopted consciously (e.g., spreading rumours about an economically rival group) stigmatising attitudes are mostly established through the involuntary process of classical conditioning (Staats et al, 1962) in the same way as phobias are. Thus if every time one hears the word ‘schizophrenic’ on TV (conditioned stimulus) there is a piece of news about murder or violence (unconditioned stimulus) one is going to associate the fear and anxiety in relation to the murder and violence (unconditioned response) to the word ‘schizophrenic’ (conditioned stimulus) in a way that the
word is going to bring about the same fear and anxiety (conditioned response) after a certain number of associations. It is likely that, to make sense of their fear, stigmatisers deploy explanatory models. The cognition ‘schizophrenics are violent’ is likely to be part of the subsequent syllogism they use as an explanatory model or a semantic backup for their underlying emotion rather than the cause of it. Offering them the cognitive model ‘schizophrenics are not violent’ is unlikely to fix the already established autonomic response circuit of arousal, fear and anxiety as mere cognitive information is likely to break to pieces when stigmatisers feel primitive, irrational fear and anxiety. They have in essence an affective problem and to fix it they need a new emotional experience rather than a replacement of their ‘explanatory model’ with one they are unable to use and which would not fit their system, however open-minded and scientific be the explanatory models of organisers of a campaign.

Nevertheless, this idea should not be taken to such extremes as to mean colluding with stigmatisers. Educational campaigns are likely to have, at the very least, the effect of challenging stigmatisers’ attitudes, proposing alternative attitudes and emphasising the presence of anti-stigmatisation pressure groups and stakeholders.

Considering the highly reinforced origin of stigmatisation, to aim at ‘erasing’ stigmatising attitudes through education is as unrealistic as to believe that nothing could be done through it. Extrapolating from social psychological research on stigmatising attitudes towards ethnic minorities one could propose that people’s awareness of the discrepancy between how they behave and how they think they should behave [towards the stigmatised] can cause some guilt and discomfort in them which, in some cases, is likely to prevent them from acting on their stigmatising attitude in future (Monteith, 1996) yet without necessarily any change in those
attitudes themselves. It is likely that what could be done by campaigns is either nothing (see references above) or a minor positive shift in moderately negative or relatively positive stereotypes which then remain open to long-term challenges by constitutional, economic, evolutionary and psychological contingencies.

9.3.2 Intervention at the Affective Level

The public’s fear and anxiety as a component of stigmatisation can theoretically either be desensitised through contact with the patients or relieved through containment or ventilation.

9.3.2.1 From contacts with patients to exodus from hostel neighbourhoods

There are reports suggesting that people who have had contacts with patients who have mental illness are less likely to endorse stigmatisation (Nunnally, 1961; Philips, 1963; Link & Cullen, 1986). Nunnally’s (1961) reports suggested that late identification of the contact person as an ex-patient is preferable to earlier identification as the latter allows participants to discount the person from the beginning as ‘mentally ill’ (Nunnally, 1961).

The claim to potential benefits of contacts should be tempered by a consideration of the characteristics of the contact person. The ever-present risk seems to be that of non-generalisation, from ‘positive’ feelings generated towards stigmatised persons encountered, to the category to which they belong. Extrapolating social psychological findings on students and ethnic minorities (Wilder, 1984; Johnston & Hewstone, 1992; Van Oudenhoven et al, 1996) to
de-stigmatisation campaigns in mental health, suggests that providing the public with contacts with a successfully treated patient is likely to create a new subtype in their mind: 'She is an exception. I have seen others worse than her.' As exposure to further strong disconfirming examples continues, new subtypes are likely to be created 'Female Educated Patients', 'Well-treated Harmless Patients' etc. but the original stereotype is maintained.

On the contrary, when the contact person is 'typical' of the stereotype with an additional characteristic, e.g., pleasantness (Wilder, 1984) or when the contact happens in equal-status cooperative contexts (Desforges et al, 1991; Van Oudenhoven et al, 1996) there may be a change in the stereotypes. To increase the chance of this generalisation the contact person has to be typical of the stereotype of his or her group (college students holding a stereotype of the students from a rival college, brought in contact with the students from that rival college who demonstrated an additional trait of pleasantness, Wilder, 1994; or Dutch pupils coming in contact with ‘typical’ Turkish pupils who interacted with them co-operatively, Van Oudenhoven et al, 1996). These findings suggest that, to fight with stigmatisation, one has to work within the stereotype as if it were a workshop and modify it from inside rather than deny or dismiss it outright. Extrapolating these social psychological research outcomes implies that a person with features typical of the stereotype of mental illness, e.g. dishevelled, fearful, anxious, unpredictable, etc. yet cooperative or helpful, make people generalise their positive impression of him/her to the category of people with mental illness. Also, co-operative interdependent interactions are likely to allow gradual desensitisation of anxieties of the group members vis-a-vis the person having a mental illness if they involve people of the same status and competence as the latter. Recent investigation indicates that contact per se in not essential and if the in-group is merely shown that friendships have developed between some other in-groups and out-group members this would
reduce stigmatisation (Wright et al, 1997) (Extended Contact Hypothesis).

If substantiated, such hypotheses have to face other challenges in the real world. Firstly, it is likely that there would be no point in bringing a patient who is a manual worker into contact with a group of chief executives as already there will be an imbalance in status and grounds for associating his lower socioeconomic status with his illness possibly reinforcing stigmatisation. In this case, contact between the stigmatiser and the stigmatised is likely to bring the relationship between them to just another level of familiarity in which though the attitudes may be seen as more ‘positive’, the stigmatising relationship may still persist in subtler forms. Goffman (1990, p. 148) proposes the notion of “phantom acceptance” in which the stigmatised are offered a lip-service normalcy, indeed a ‘phantom normalcy’ in which there is as if a ‘contract’ between the stigmatised and the stigmatiser to declare that the former is ‘normal’ provided that the stigmatised recognises his ‘proper place’ — A sort of tacit agreement in which a show of acceptance is put on stage, precarious enough to break down if the stigmatised would not know its limits and wish to draw, in practice, on all the credit he has been accorded theoretically.

Secondly, to work from within the stereotype to promote its improvement may paradoxically reinforce it as there is a fine line between using the stereotype for this purpose without giving it undue salience and using it in such a way that leads to its further reification and so one is likely to risk marching in dangerous territories. Research by Desforges et al (1991) suggests that participants doing a co-operative task with [a recovered] ‘former mental patient’ of equal status (in the experiment, students in dyadic groups interacted with a fellow student they were told was a ‘former mental patient’) had their attitudes improved, subtyping did not happen (as the agenda of the co-operative task did not allow participants to discuss personal matters about the ‘former
mental patient' with her) and positive attitudes were generalised to the category of 'mental patients'. This study suffers from Enhanced Social Desirability Effect. Further, no measurement of long-term effects was made. Also, the supposed 'former mental patient' was a confederate who, by the fact of being a student of the same university as that of the participants, could have attracted sympathy towards the group of patients with mental illness immediately following the experiment. Yet, the results are consistent with other studies (e.g., Blanchard et al 1975) about the importance, in improving prejudicial attitudes, of encounters between the stigmatised and people of similar competence, rank or profession.

Thirdly, there are reports indicating that a larger number of examples are required to confirm a positive attribute in a stereotype and fewer contrary examples to disconfirm it (e.g., Rothbart and Park, 1986). These findings are consistent with previous data that people tend to weight negative information more heavily than positive information (Kanouse & Hanson, 1972). As such exposure to a great number of 'positive' contacts can be easily undone by the image of the homeless patients with mental illness in the streets; with few salient items of news about a murder by a patient with mental illness or with a film involving the audience in an emotional contact with characters not elaborated according to social science laboratory formulas.

Contacts between patients and the public could be fraught with other problems. The study by Wolff et al (1996a) reports on a campaign of public education which included efforts to promote contacts between local residents and patients in residential facilities in an experimental street compared to a control street in London. The authors report 'increased contact and even friendship' between local patients and neighbours and take the results as indication of "improvement in overall attitudes and behaviour towards the mentally ill" taking for granted in
this way, the generalisation from a few local patients (5 out of 8 patients) to the category of patients with mental illness. A finding that the study quickly passes by without interpretation and which further qualifies the significance of the outcome is that whilst both experimental and control streets were within the same area, Lambeth, mobility out of the sample from the experimental street at follow-up, i.e., after the arrival of the mental health hostels and the associated campaign, was significantly higher than that out of the sample from the control street (Table 9.1).

<table>
<thead>
<tr>
<th>Mobility out of Control and Experimental Streets at the End of Campaign</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total of both Samples</strong></td>
</tr>
<tr>
<td>(n = 215)</td>
</tr>
<tr>
<td><strong>Control street</strong></td>
</tr>
<tr>
<td>(n = 113)</td>
</tr>
<tr>
<td><strong>Experimental street</strong></td>
</tr>
<tr>
<td>(n = 102)</td>
</tr>
<tr>
<td>Moved out</td>
</tr>
<tr>
<td>n</td>
</tr>
<tr>
<td>66</td>
</tr>
</tbody>
</table>

Table 9.1 Mobility out of control and experimental streets (Data derived from Wolff et al, 1996a and re-subjected to statistical analysis). (Chi² = 3.92, DF = 1, \( P < 0.05 \))

The authors do not refer to the significance of this outward mobility, instead, they mention, in passing, that those who subsequently moved had shown no overall difference in stigmatising attitude pre-campaign compared with other neighbours. Yet the likelihood that their attitudes were affected more negatively, subsequent to the arrival of the hostels and the associated publicity, or that they corresponded to the subgroup who stigmatise in effect, and not on survey papers, should not be left unmentioned. There is no indication (and Wolff et al’s paper does not mention it in the first place) that there were any issues such as poor housing or excessive noise in the experimental as opposed to the control street which could have made the targeted people
move out of the experimental street. Of course, the significant difference in mobility might have occurred due to the presence of a more mobile group in the experimental street at baseline. Mobility is likely to be determined by sociodemographic factors such as social class and ethnicity. One then has to argue that there must have been significant differences in ethnic and social class composition of the two samples which would already cast serious doubts on the comparability of results of the two samples in the study.

Data obtained from the authors (personal communication from Dr Wolff) subsequent to the publication of the paper, actually confirmed that what is described in that paper as “differences in the social class and ethnic mix of the neighbours” (p. 445) refers to highly significant disparities in the samples in both ethnic ($\chi^2 = 16.2; \text{DF}=2; p < 0.001$) and social class terms ($\chi^2 = 12.8; \text{DF}=1; p < 0.001$) though, as the authors mentioned in the paper, they had no control over the siting of the experiment. Having said this, still one cannot conclude that the significant excess exodus from the experimental street was merely due to such class and ethnicity differences. Though causality between contact and excess exodus can not be proved, consideration of a significant mobility out of an experimental group should be part of interpretation of any such research.

The idea that a significant additional number of neighbours left the experimental street to get away from the hostels becomes more probable when one considers that, according to the authors, 20% of the respondents at the initial interviews expressed concerns one of which was worry about “a drop in house prices”(Wolff et al, 1996 b, p. 69) if patients were moved from hospitals into units in their areas. This makes it harder to deny that though on one hand ‘contact’ increased between some neighbours and patients, on the other hand the presence of the hostel and further publicity
about it could have played a role in the excess exodus. Those who move out of an area to avoid patients can have their negative attitudes reinforced by the mere act of distancing themselves from what makes them uncomfortable, which would give them a ‘feeling of relief’. Inasmuch as avoidance is likely to become entrenched through negative reinforcement each episode is likely to worsen stigmatisation. Segal et al (1980) report that people with mental illness may seem more integrated in neighbourhoods with little social cohesion. Apart from anything else, the fact that there was more mobility and so less social cohesion in the experimental street casts further doubt on the reported significance of the social integration of patients in the study. In this regard, Goffinan’s (1963) concept of “phantom normalcy” is also noteworthy.

The dilemma is clear: on one hand, if we present the public with dramatically improved patients, they are likely to subtype them as ‘exceptions’ while sustaining their stereotype. On the other hand, if we work from within the stereotype and present the public with ‘typical’ patients there might be some positive shift in the stereotype but there is also a risk of reinforcing the stereotype.

9.3.2.2 Focusing on the feelings of the public

Experiments show that, for an anti-stigmatising message to be successful, it should reduce anxieties, offer solutions, be expressed with certainty (even if later scientific findings make it necessary to refute messages given previously) and not just wipe out public’s views of mental illness but replace them with new information (Nunnally, 1961).

If contacts with patients are fraught with dilemmas, so how could one act on the affective level
of stigmatising attitudes? When one reflects on the relative success of local targeted efforts at de-
stigmatisation (Lynch, 1987; Quicke, Beasley & Morrison, 1990) one possibility is that in these
workshop-like events there may have been more possibility for ventilation of anxieties of some
of the targeted groups. These campaigns, associated with ‘discussion’ with peers and teachers,
reported a more pronounced improvement in ‘preconceptions’. There has been no adequate
interpretation as to why this should be so yet the likelihood is that during some of these
unstructured ‘discussions’ the fear and anxiety of participants are more or less ventilated. It
would not be adequate to tell people that patients with mental illness are not dangerous as what
they need is to feel free to say how fearful they were the other day when they heard about a
person with schizophrenia attacking someone in the street. The real concern for patients starts
by paying attention to the affective content of the public attitudes. De-stigmatisation, if it is ever
to be successful, needs to provide forums for the expression of fears in which people can speak
up, ask questions, challenge and communicate their worries. If taken seriously and relieved of
their anxiety they are likely to take seriously the same feelings in the patients. For this purpose
large group meetings with the help of a facilitator, psychotherapist or trained social worker allow
the ventilation of public feelings in neighbourhood centres, youth organisations, community
services, churches, libraries and schools.

9.3.2.3 Labouring in the media and arts’ workshops

An independent study by Glasgow Media Group (Philo, 1993) showed that images of violence
by patients predominate in both fictional and non-fictional media output. In the study about forty
per cent of people considered that those with illnesses such as schizophrenia were quite likely to
be violent and gave the media as the source of their belief. Twenty-one per cent of the total sample (included in the 40 per cent) had ‘non violent’ experiences with patients yet these experiences were overridden by ‘violent’ media messages. It is likely that a higher proportion of people actually internalise the images proffered by the media and then see, in that light, patients they encounter without being subjectively aware that they are being influenced by images they have incorporated and whose source they have subsequently forgotten. In a later study, Philo (1996) reported that violence appears in 66% of items about mental illness on television.

The Mental Health Foundation, Manic Depression Fellowship, National Schizophrenia Fellowship, MIND and the MACA (Mental After-Care Association), five leading mental health associations in Britain have joined forces to form Mediawatch. Mediawatch challenges exaggerated portrayals of mental illness, monitor media coverage and inappropriate use of language and make constructive comments on story plots. Mediawatch also has invited the public to do so by writing to the Press Complaints Commission, the Advertising Standards Authority, the Broadcasting Standards Commission, BBC Viewers and Listeners Correspondence, the Independent Television Commission and the Radio Authority. Yet messages in the Media such as “Killings by Mentally Ill Will Continue”; “Psycho Man-hater Butchered Lover”; “The Government Schizophrenic Policy” persist in the media (Mental Health Foundation, 1997, p. 1). If we consider that in terms of charity giving mental health remains one of the least popular, we understand why according to newspaper and television companies people rarely complain. In 1993, mental health charities raised a total of £16 million; chest and heart £50 million and cancer charities £160 (Mental Health Foundation, 1997).

It seems uncontentious that the portrayals of mental illness in advertisement, news and films are
exploited in the service of economic gain. Also, the arts' agenda is to re-present what is not usual in order to exist as the arts by enlarging its audience appeal. The arts would not identify their function as copying reality but modifying and re-presenting it in new forms. Though giving concerts or setting up creative workshops and exhibition as a recognition of the value of patients with mental illness are worthwhile, another aspect of work on the affective component of the stigmatising attitude would be to acquire the weapon: producing works of art, writing popular novels or making films with the help of interested patients and psychiatrists in collaboration with artists. These works of art or literature are likely to act on the feelings of the public at a level where the affective component of their attitude resides rather than at a cognitive level. Examples are the novel *The Song of Hope* in press in Britain, depicting in popular literary narrative, the struggle and revaluation of a number of patients with mental illness and *Marie Butler Story*, a movie produced by CBS in the US in collaboration with National Alliance for the Mentally Ill (NAMI) about the sacrifices and successes of an institutionalised woman. These books and films provide few factual data but work on the affective level of the mind of the readers and viewers. The risk of subtyping is likely to reduce when works of art depict a ‘typical’ patient who improves and develops an additional positive trait.

In conclusion, a new affective experience for the public is likely to be promoted by attending to emotions of stigmatisers. When a cognitive message is subsumed in a work of art, it is important to take heed of how it is communicated as this how is likely to carry something of the emotional charges it contains. This is why work with TV professionals needs to be a business of having anti-stigmatising messages subsumed under new emotional experiences for the viewers. Generous Media Awards would guarantee co-operation.
9.3.3 Legislative Intervention

Theoretically legislation both reflects and forms public attitudes. To date, there has been no experimental evidence showing that anti-discrimination legislation would or would not change public stereotypes. Rupert Brown mentions that anti-discrimination legislation “helps to create a new social climate in which more tolerant norms can emerge. Thus the significance of ...the British Race and Sex Discrimination Acts of 1965 and 1975 may not have been that they were in themselves effective in outlawing discrimination. Indeed, many..employers did their damnedest to avoid having to implement them for years. But they did have a profound impact on people’s attitudes so that it became increasingly less acceptable to discriminate against minority groups or women openly.” (Brown, 1995, pp. 238-9).

It is possible that new laws contrasting with personal attitudes would challenge people into debate and self-questioning. To avoid the legal sanction, people have to bring their behaviour at least in line with the law and this would cause dissonance with the previous attitude (Festinger, 1957) The final outcome, at least in some cases, is likely to be a change of attitudes but, in most instances, the public would choose the easiest route — holding on to their pre-existing attitudes while justifying their new behaviour with the necessity to avoid the sanctions in force. As such anti-discrimination laws acting as symbols of ‘parental’ authority and judgment could merely repress stigmatising attitudes but, at the same time, are likely to function as institutional support (Allport, 1954), protecting patients from the injustice inherent in stigmatisation and increasing the public tendency, through internalisation of a new behavioural norm (even while holding to the old attitude) to act in a more equalitarian manner.
The exercise of discrimination can be subtle as sitting apart or snubbing, or flagrant such as rejection of an employment application or refusing to rent accommodation or not allowing people on public premises. The legislative system needs to be encouraged and/or put under pressure through advocacy and lobbying by anti-stigmatisation watch-dog cells created within psychiatric associations or advocacy units. These anti-stigmatisation watchdogs, networking lawyers, MPs and human right organisations should identify gaps in the legal protection and promote reforming, enacting and reinforcing laws which recognise compensatory privileges for patients and allocate sanctions on gross discriminatory behaviour towards patients with mental health problems. The watchdogs and legislators should make sure that patients are involved in decisions and that circumstances are provided which help users assert their rights. To this end, political activism by users needs to be supported.

Legislation should also promote positive discrimination towards patients with mental illness in the sense that employers should be rewarded for having a quota of their employees from those who suffer from mental illness and for providing training options and specific sick leave provisions; landlords have to have more obligation towards patients and insurance companies have some commitment to include cover for treatment of mental illness on their mainstream policies as a means of recognising the value of people with mental illness, its ubiquity and acceptability.

9.3.4 Political Intervention: Towards a Better Society

The choice of a certain political ideology is likely to respond, among others, to psychological needs such as need to dominate, control, coerce or the wish to share, promote compassion,
equality and interdependence. Pathology in members of a nation is likely to have to do, among other factors, with biopsychosocial factors (Engel, 1980) including the nature of the political system, civil liberties and social justice which reflect and are, in turn, reflected by the quality of upbringing and emotional stability within families in that society. It is likely that a society based on warmth and intimacy rather than dominance and power has less need to systematically pursue self-interest and so to stigmatise. Also, in environments where self-interest is intensely pursued, the degree of stigmatisation is likely to rise with consequent poorer prognosis for the patients in that they are perceived as a bigger threat to self-interest and further rejected. Attitude of the state to the extent and implications of inter-individual competition is likely to influence the citizens’ attitudes and vice versa. For example, intervention of the state to limit ruthless, cruel, extravagant or uncontrolled economic take-overs that would threaten the survival of individuals and smaller businesses and sacrifice substantial budget on anti-discriminatory activities would be a message to the whole society on the concern about effects of aggressive competition and/or destruction of the chances of the weak.

Equalitarian non-competitive environments which encourage cooperative interdependence of all people in society for a superordinate higher cause rewarding the whole community reduces inter-group hostility and prejudice (Sherif, 1966; Amir, 1976; Gaertner et al, 1993). The political philosophy of the state and its emphasis on the unity and interdependence of members of the large society for a higher cause is likely to moderate self-serving behaviour of its citizens and promote tolerance and respect for all groups in that society including the weak and the vulnerable who are then seen as allies in the service of the higher cause. This last part of a de-stigmatisation programme is ambitious enough to be a task to which all citizens need to contribute, the task of the third millennium.
In job interviews and similar contexts an important question all of us need to answer is whether the existential value of a person who has achieved more without having a mental illness is necessarily higher than the existential value of someone who has achieved less while having a mental illness. The real difficulties in adjustment of some people with a mental illness is what other applicants too would have had on average had they developed it and so cannot be used as a basis for measuring the personal value of people with such illnesses. One might ask whether it is not the case that rejecting the latter applicants is indeed promoting stigmatisation however ‘justified’ may seem the arguments of employers who wish to offer the job to the ‘best applicant’. This is also true of some ethnic minorities who have to struggle in isolation and under the pressure of cultural adaptation, having experienced the ravages of war and political oppression in their own countries. Their possibly lower achievement in a new culture would be similar to what other applicants from the latter culture would have done were they to struggle under similar circumstances in another environment and so can not be held as a measure of their real merit. What we lack is perhaps a political ideology which would allow for consideration of people’s life histories as well as how much they have achieved. Though meritocracy is to be respected in principle, it can be inevitably exploited in the service of satisfying sinister motives when a stigmatiser knows that by following it s/he would exclude a large number of the stigmatised. As such meritocracy can be deployed as an instrument of stigmatisation.

9.3.5 Linguistic Intervention: Challenging the Denial of Personal Stigmatising Attitudes

Yet, the biggest misunderstanding in debates on political correctness is the misconceived idea that
the whole aim of linguistic intervention is merely to reduce the verbal disrespect towards the stigmatised rather than using the discourse as a tactic to challenge existing attitudes and as an invitation to adopt new attitudes.

In general, the future status of a new designation depends on the features of the group with which it is associated. If the group moves into the mainstream of society and is given respect the new designation becomes prestigious. If the new group is excluded from the mainstream of society or its status declines, the new linguistic form will become stigmatised (Labov, 1972). As such new terms which are introduced will be incorporated in the dynamics of the social system and become semantically biased. There is a well-known history of repetitive changes of designations for patients with learning difficulty, each new term acquiring the discrediting connotations of the previous terms after some time. Yet, the effect of change of a designation is desirable even if temporary. “Telling people that their renaming practices are futile and they should therefore stick to existing labels, however unsatisfactory and pejorative they have become, is like saying to someone with a chronic headache what’s the point of taking aspirin? You know you’ll have another headache later”! (Cameron, 1995, p. 147).

Reviewing brochures of advocacy organisations such as MIND shows that linguistic intervention is one of the requests of patients and advocates and this was confirmed by some patients and relatives’ remarks in my survey “I don’t like that expression [schizophrenic] because it’s a very old word.” If one supposes that de-stigmatisation starts by paying attention to the requests of the stigmatised one needs to take heed of the message. Accommodating their request is a sign of solidarity with users. Their request does not need to be taken as a mere wish for a change of designation from e.g. ‘schizophrenic’ to ‘a person with schizophrenia’ (Haghighat & Littlewood...
1995) in as much as the request can also be seen as a tacit invitation to stigmatisers to review the stereotype they have of patients in their mind, indeed a request for a re-consideration of stigmatisers’ personal attitudes.

A linguistic debate becomes, as such, a reminder of stigmatisation, an instrument to induce constant questioning of personal attitudes towards the stigmatised, a self-enquiry device which challenges the denial. One can use the preferred linguistic forms as a political message for inviting further debates in order to create sensitivity towards and awareness of one’s and others’ stigmatising attitudes. As such linguistic debate, as an instrument, rather as an aim, as a tactic rather than a strategy, contributes to the maintenance of what a healthy society needs to constantly promote — monitoring the intensity and variety of its stigmatising attitudes. This means that campaigns of de-stigmatisation are not to be programmes that ‘end’ after some time, but continuous, non-stop, open ended projects aiming at keeping alive thought processes that moderate and humanise our urge to survive in a socially competitive world.

Would linguistic intervention help change linguistic practices? It would be incorrect to suppose that formal or informal acts of prescription (such as guidelines or objecting to certain usages at meetings) have an immediate or overwhelming effect on people’s linguistic practices; there will be resistance and inertia as well as acceptance, and language practices that result are extremely variable (Cameron, 1995) but they undoubtedly incite debates and self-questioning. Would linguistic intervention, on its own, promote fundamental psychological changes? There are a few scientific experiments which could give precise information about the “rearrangement of psychological structures in correlation with the restructuring of the world of symbols or their associated connotations” (Bering, 1992, p. 195). One is the finding that campaigns of language
planning have resulted in significant psychological changes in the stigmatised when seen from the perspective of earlier experiments in the 1970s. In those experiments people were sent journal articles to evaluate. Some received the articles with the name of a man as author, others received exactly the same articles with the name of a woman author. All participants, both men and women, evaluated the articles as more scientific when they believed that the author was a man (Romaine, 1994). A more recent experiment at Harvard examined whether those who have reformed their use of male generics have also changed their thought processes. Undergraduates who either had or had not reformed their usage in their written work were asked to draw pictures to go with sentences such as an unhappy person could still have a smile on his/her/their face. The results showed that although there were still more male pictures regardless of the pronoun used and regardless of whether the participant had reformed their written usage, women (rather than men) who had reformed their usage produced more female drawings regardless of the pronoun used (Romaine, 1994).

Would linguistic intervention, on its own, promote fundamental social changes? Following feminist campaigns for nonsexist usages starting in the 1960s in the US there have been more changes in language practices but only modest improvements in women's status, salaries and employment rate in the US (Cooper, 1989). This consists of smaller wage difference between females and males and an increasing proportion of women in higher paying jobs. Yet, what Cooper would not consider is that these modest improvements are likely to have been promoted with the help of the associated discourse even though there is no evidence for or against it.

Linguistic intervention is promotion of a particular discourse in society's order of discourses. Patients' political and ideological invitations, such as solidarity with fellow patients
(Schizophrenia-sufferers are my mates), reclaiming neutral connotations for the illness *(This is an illness like any other)*, the universality of suffering *(Schizophrenia sufferer' means an illness anyone can suffer from and it is not only for certain people)* and reclaiming *(Schizophrenics are chummy)* should be supported to promote a user created emancipatory discourse. Developing a new discourse is part of an effort to empower through asserting, contradicting and challenging the established order of discourses.

An intervention, for example, a re-naming practice demonstrates concern about social structures, values and relations vis-a-vis patients. These discourses help patients master their sense of powerlessness. Referring to a ‘schizophrenic’ as ‘a person with experience of schizophrenia’ asserts that present orders of discourse are not immutable. As such, language awareness and intervention facilitate an emancipatory discourse which may “challenge, break through, and ... ultimately transform the dominant orders of discourse, as part of the struggle of oppressed social groupings against the dominant bloc” (Fairclough, 1989, 239-40). According to Dahrendorf (1959) and his conflict theory change results from the competing interests and values of different groups each contending with the others for power. Thus each instance of linguistic planning is, at least in part, demonstrative of a power struggle with those in power trying to maintain the existing system and the oppressed trying to change the system to increase their power (Cooper, 1989, p. 179). The ability to change terminology may not cause change but be an example of growing political power (Bendix, 1979). It is such that linguistic intervention by suggesting that existing orders of discourse are not unchangeable establishes a political agenda in the negotiation and fight for liberation and empowers people as producers of a new discourse to engage in struggle, to challenge, question and take further action in situations where they habitually consent to existing orders of discourse.
9.3.6 Intellectual and Cultural Intervention

Novel interpretations of evolution would limit deterministic features imposed on our views by current interpretations which can tacitly serve stigmatisers. Sociobiology considers a variety of animal and human behaviours and tries to interpret them along the lines of the theory of survival of ‘selfish genes’ which use our bodies as robots making us behave in ways leading to these genes’ ruthless self-replication. Explaining stigmatisation as one aspect of a genetic behavioural programme for survival of genes implies that isolating and rejecting the stigmatised is a natural evolutionary process, ‘justifying’ prejudice as something ‘biological’ and ‘innate’ and reifying stigmatisation as a more or less deterministic ideology.

Examples of human behaviour analysed by sociobiologists (Wilson, 1975; Trivers, 1985; Ridley & Dawkins, 1981; Rushton, 1989) happen to represent, not necessarily for an innocent reason, the typical stigmatisers’ or dominant discourse — such as exerting prejudice in order to maintain genetic similarity (i.e. ‘purity’ of races); reproductive victory of stronger males for the species pool of genes to replicate optimally; and altruism (in a struggle to get their theory off the hook of the criticisms their opponents had brought up as to why then humans sacrifice themselves for people of a different genetic makeup). Behaviours such as solidarity of the weak, mob movements, revolutions, social protests (possible behaviours of the stigmatised) though subjectable to the same theoretical explanations are not, as frequently, given to analysis. Why? Here one can observe how the theory is being employed to analyse and explain the behaviours of the oppressors rather that of the oppressed and how sociobiological ideas are actually or potentially used to provide theoretical backup for the discourse of power holders.
The fact that the nature is what it is does not mean that one could not use judgment or morality to decide what is good for humans (Barash & Lipton, 1985). Yet, those who need to stigmatise in order to dominate would either downgrade the idea of morality as the instrument used by the weak or recommend a new ‘morality’ in the service of power: "one has duties only toward one's equals; one may act as one sees fit towards beings of a lower rank, toward everything foreign to one” (Nietzsche, 1886). As such ‘old’ and ‘new’ morality can both be used in the service of domination. Encyclopaedia Britannica (1998) mentions that “two books were standard issue for the rucksacks of German soldiers during World War I, Thus Spoke Zarathustra [by Nietzsche] and The Gospel According to St. John.” Later on, Nietzsche’s views and social Darwinism (used to proclaim that helping the weak was against natural selection) was employed by the Nazi system to provide ideological underpinnings for the thesis of superiority of Aryan races (Encyclopaedia Britannica, 1998) and extermination of six million Jews.

Though self-interest remains the basis of stigmatisation, the genetic origin of stigmatisation is not as deterministic as sometimes implied. If genes can guarantee their own survival through encouraging reproduction of people with similar or closely related genes what about the high level of violence in families? Also some people choose dangerous hobbies and pursuits for self-fulfilment purposes even if they might lose their lives in the process which, of course, would not lead to any genetic interest. There is no evidence that numbers of such people are reducing nor that the ultimate ‘logic’ in having these dangerous hobbies is necessarily to attract the opposite sex and propagate one’s genes. Also there are people who choose not having children, as such, cutting back, in effect, the ‘hope’ of their species genes for self-replication, while they compete ardently on economic grounds and there is no more reason to believe that they do so (unawares) for others to procreate on their behalf (like worker bees who sacrifice their fertility for the sake
of their queen to procreate) than they do so on account of their own fulfilment.

Viruses, protozoa and even higher animals are over-restricted by the fiat of their genome and lack the humans’ capacity for intervention in the workings of their own genes or gene products intellectually, ideologically or scientifically. This ‘democratisation’ of choice from viruses to fishes and from the latter to humans is a less recognised aspect of evolution which has provided humans with more choices and freedom from the hegemony of genes and offered, through evolution, more space, options and alternatives in choosing their own behaviour and destiny. The unrelenting tendency of evolution to release humankind from biological constraints is of pivotal significance for reconstruction of a new discourse for modern evolution. It is our ideology which decides how we are going to use our relative freedom from biological imperatives that still restrict animal kingdom. Ideology is not genetic and even if it is proved to be so there is always choice between countervailing ones.

In ideologically favourable societies, opting for non-stigmatising behaviours could have reproductive value. A change of culture may render ‘ancient’ adaptive mechanisms irrelevant for survival in modern circumstances. Culture can design environments which would not lead to the selection of stigmatisers but that of co-operative interdependent protagonists. Indeed, groups whose members cooperate with one another may out-produce groups composed of selfish individuals (Sober & Wilson, 1998). What can hinder a more equitable approach to other humans can only be the vestiges, in our genome, of our animal evolutionary heritage while the deployment of our newly acquired evolutionary autonomy can help us develop cultures which promote de-stigmatisation.
Final Remarks

As a final note, I would like to critically appraise the limitations of the methods and instruments I used in this piece of research.

A point worthy of reiteration is that as stigmatisation is likely to be more intense in poorer economic conditions, one can suggest, on the basis of high deprivation indices in South Camden and Islington, that the results of the survey may be, on the one hand, an over-estimation of the average level of stigmatisation in the UK inner city areas. On the other hand, some other factors might have led to an under-estimation of the level of stigmatisation. The definition of the target population of patients excluded those who were more or less permanently or very frequently ill and who might actually be exposed to higher degrees of stigmatisation. Also, those patients or relatives who were untraceable could have moved out of their original addresses, not due to delusions about neighbours or spirits or personal reasons, but also or uniquely in relation to social stigmatisation. Further, those people who refused to participate (about 30% of patients and 16% of relatives target populations) may have been the butt of more intense social stigmatisation and, precisely for that reason, avoided participating in a survey which reminded them of their unbearable experiences. In addition, people at times tend to report how they or most people should behave rather than how they actually behave. Some participants in the survey mentioned that, in their responses, what they tended to consider was not always how themselves or most people actually behave but how they should behave. Taken together, these factors which might have led to an under-estimation of the level of stigmatisation, may compensate for the over-estimation due to economic deprivation to such a degree that the outcome of the study can be more or less representative of at least inner city areas in the UK, though this cannot be taken for
Throughout this work, tests suitable for ordinal data (Mann Whitney, Kruskal Wallis, Wilcoxon, Friedman) were used when appropriate. When t tests, factor analysis and linear regression were applied to treat ordinal data, an attempt was made to stress the fact that these tests have been originally devised to assess quantitative data (p 180; pp 187-188; p 214; p 255). Yet, they are commonly applied to Likert scales by statisticians and non-statisticians, with the understanding that the resulting data are going to be approximations since there is no reason to believe that the distance between one point of an ordinal scale and the next is necessarily the same as the one between that point and the one before. Though some distortion may be done to the data, this practice done with caution is reasonably safe especially for Likert scales with a higher number of scale points (Rodeghier, 1996). For reasons described earlier (p 179), a four-point Likert was used in this survey, and consequently, the data should be interpreted with due caution.

Another area worth considering is that, in the survey, patients (and relatives) who, either themselves or their family member, had a history of being ill with schizophrenia, were asked to tell how most people would react to the person described in the study vignette. The latter person was presented as a twenty year old man who is not married, has a job and lives with his parents, and who, one day, becomes ill and his doctor says he has schizophrenia. This assumes that patients and relatives respectively would identify themselves (or their family member) with the person described in the vignette, in order that we can take their responses as representing their own perception of stigmatisation towards the patient participating in the survey or the currently ill patient in their family. Also, one must emphasise that the majority of questions in the questionnaires on perception of stigmatisation (and predisposition to enact stigmatisation)
measure perception (or predisposition to enact) *unjustified discrimination* (in the form of action, thought or feeling) as a major component of stigmatisation.

As far as factor analysis is concerned, the allocation of a name to the underlying concept in each factor is necessary in order to delineate the concept extracted, yet it remains a purely subjective exercise which may be influenced by the experimenter’s original hypothesis. Also, in relation to the same factor analysis, the allocation of terms such as ‘emotional exclusion’, ‘transactional exclusion’ and ‘exclusion justification’ have, of course, not been done as a means of stigmatising the public but as an attempt to understand the core components of stigmatising attitudes, though these terms may imply an anti-stigmatising discourse in the experimenter’s mind. It is also to be emphasised that the number and nature of the factors extracted can vary depending on the number of participants and type of questions included in questionnaires and it is hoped that future students of stigmatisation would further refine the findings of this piece of research. In this relation, they may choose to use the whole twenty-item scale (instead of the final thirteen-item scale) to verify or replicate the extracted factors.

And finally, though the study of sociolinguistics of stigmatisation is a major component of this work, I carry the guilt of following on the medical tradition and referring to some participants in the survey as ‘patients’. I could have referred to them as users, though a recent report (Ritchie et al, 2000, Psychiatric Bulletin, 24, 447-450) indicates that patients prefer to be referred to as ‘patients’ rather than ‘users’ in psychiatrist-patient encounters. It is likely that my professional identity as a psychiatrist has influenced my choice of terminology. Further, as mentioned previously, what matters in a discourse is not its form but its content and raison-d’être. Considering my genuine concern for respecting the dignity of the latter group, I would like to make it clear that my use of the term ‘patient’ throughout this text has been purely denotative.
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Appendix I

Consent Form

What do you think about psychiatric illness?

Thank you very much for giving us your opinion. This is a research project carried out by Dr Haghighat at the University College London Medical School. It is confidential and we do not require your name. Your decision whether or not to join in the research will not influence your medical care. You can withdraw from the survey at any time. If you have any questions about the research, do please ask Dr Haghighat.

If you have agreed to participate please sign below.

........................................

Signature of Participant
Appendix II

Sociodemographic Data Sheet

It would be helpful to know a little about you. Please answer these questions. We do not need your name.

1. How old are you?..................................

Now please tick the appropriate box.

2. Are you male or female? Male? □ Female? □


Other - Please specify .................................................................

5. Which country were you born in? ...........................................................................................................

6. What was your first language? .............................................................................................................

7. What is your occupation? Please be as precise as possible (If you are a housewife, please state the occupation of your husband)....................................................................................................

8. What was your father's occupation? Please be as precise as possible.............................................

9. How many years of education have you had? ......................................................................................

10. Which exams did you pass or certificate or degree did you get?......................................................
Appendix III

Questionnaires

A) (Perceived Stigmatisation)

Thank you for answering some questions about a person who becomes ill. Please read carefully and then answer the questions about him. There are many differences of opinion on this subject. You can be sure that many people agree with your choice. There are no right or wrong answers: we are simply interested in your opinion. Please answer every item.

This young man is twenty years old. He is not married, has a job and lives with his parents. One day he becomes ill and his doctor says he is a person with schizophrenia.

Now what do you think most people (but not yourself) would actually do or feel about this person if they knew his history. Please put a tick in the appropriate box for each question.
1. Would most people be happy to sit next to this man on a bus?

| Yes, very happy | Yes, quite happy | No, not so happy | No, not all happy |

2. Would most people be happy if he were to work together with them in their workplace?

| Yes, very happy | Yes, quite happy | No, not so happy | No, not all happy |

3. Would most people think this man is a bad person?

| Definitely yes | Possibly yes | Perhaps no | Definitely no |

4. Would most people be happy if this person became the teacher of their children?

| Yes, very happy | Yes, quite happy | No, not so happy | No, not all happy |

5. Do most people think he has developed his condition to avoid the difficult problems of everyday life?

| Definitely yes | Possibly yes | Perhaps no | Definitely no |
6. Would most people think he should stay in hospital for his whole life?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>

7. Do most people think his condition is a punishment for bad deeds?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>

8. Would most people be happy if he married their sister?

<table>
<thead>
<tr>
<th>Yes, very happy</th>
<th>Yes, quite happy</th>
<th>No, not so happy</th>
<th>No, not all happy</th>
</tr>
</thead>
</table>

9. Would most people be happy to eat food which he has cooked?

<table>
<thead>
<tr>
<th>Yes, very happy</th>
<th>Yes, quite happy</th>
<th>No, not so happy</th>
<th>No, not all happy</th>
</tr>
</thead>
</table>

10. Do most people think one of the main causes of his condition is a lack of moral strength or will power?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>

399
11. Would most people be frightened if this man came to live next door to them?

| Yes, very frightened | Yes, quite frightened | No, not so frightened | No, not at all frightened |

12. Would most people avoid talking to him if possible?

| Definitely yes | Possibly yes | Perhaps no | Definitely no |

13. Do most people think he has become a failure in his life?

| Definitely yes | Possibly yes | Perhaps no | Definitely no |

*Thank you for completing this part. Please give it back.*
B) (Assessment of Predisposition to Enact Stigmatisation)

Now what do you think about this same person yourself. Remember these questions are similar to the previous ones, but here you are asked what you think of the same person.

1. Would you be happy to sit next to this man on a bus?

<table>
<thead>
<tr>
<th>Yes, very happy</th>
<th>Yes, quite happy</th>
<th>No, not so happy</th>
<th>No, not all happy</th>
</tr>
</thead>
</table>

2. Would you be happy if he were to work together with you in your workplace? (If you do not have a job, answer as if you did).

<table>
<thead>
<tr>
<th>Yes, very happy</th>
<th>Yes, quite happy</th>
<th>No, not so happy</th>
<th>No, not all happy</th>
</tr>
</thead>
</table>

3. Do you think this man is a bad person?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>

4. Would you smile at this man and other people every time you meet them?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

401
5. Would you be happy if this person became the teacher of your children?

[Table]
| Yes, very happy | Yes, quite happy | No, not so happy | No, not all happy |

6. If you say to this person or other people that you will do something, do you keep your promise no matter how inconvenient it might be?

[Table]
| Yes | No |

7. Do you think he has developed his condition to avoid the difficult problems of everyday life?

[Table]
| Definitely yes | Possibly yes | Perhaps no | Definitely no |

8. Do you think he should stay in hospital for his whole life?

[Table]
| Definitely yes | Possibly yes | Perhaps no | Definitely no |

9. Do you always practise what you would preach to this person or anyone else?

[Table]
| Yes | No |
10. Do you think his condition is a punishment for bad deeds?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>

11. Would you be happy if he married your sister?

<table>
<thead>
<tr>
<th>Yes, very happy</th>
<th>Yes, quite happy</th>
<th>No, not so happy</th>
<th>No, not all happy</th>
</tr>
</thead>
</table>

12. Would you be happy to eat food which he has cooked?

<table>
<thead>
<tr>
<th>Yes, very happy</th>
<th>Yes, quite happy</th>
<th>No, not so happy</th>
<th>No, not all happy</th>
</tr>
</thead>
</table>

13. Would you ever lie to this man and or other people?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

14. Do you think one of the main causes of his condition is a lack of moral strength or will power?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>
15. Would you be frightened if this man came to live next door to you?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>

16. Would you avoid talking to him if possible?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>

17. Do you think he has become a failure in his life?

<table>
<thead>
<tr>
<th>Definitely yes</th>
<th>Possibly yes</th>
<th>Perhaps no</th>
<th>Definitely no</th>
</tr>
</thead>
</table>

*Thank you for completing this part. Please give it back.*
C) Linguistic Questionnaire

1. *When you speak about people who have schizophrenia, how do you usually refer to them?*

   Please specify...................................................

2. *If by chance you develop schizophrenia (or if you have already developed it) how would you like other people to call those who have schizophrenia?*

   Please specify ..................................................

3. *When you speak about those who have schizophrenia, which of the following expressions would you prefer to use?*

<table>
<thead>
<tr>
<th>People Having Schizophrenia</th>
<th>Schizophrenia Sufferers</th>
<th>Schizophrenics</th>
<th>People with Schizophrenia</th>
</tr>
</thead>
</table>

405
4. Could you please write in a few lines why you prefer that expression in question 3?

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

5. If, by chance, you develop schizophrenia (or if you have already developed it) how would you like other people to refer to you when talking about you among themselves?

<table>
<thead>
<tr>
<th>Person Having Schizophrenia</th>
<th>Schizophrenia Sufferer</th>
<th>Schizophrenic</th>
<th>Person with Schizophrenia</th>
</tr>
</thead>
</table>

6. Could you please write in a few lines why you would prefer to be called that?

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

406
Please tick the box of your choice in each of the following questions.

Consider a person who has schizophrenia:

7. If someone calls the individual a person having schizophrenia, that would be:

<table>
<thead>
<tr>
<th>Very much devaluing</th>
<th>A little devaluing</th>
<th>Not much devaluing</th>
<th>Not at all devaluing</th>
</tr>
</thead>
</table>

8. If someone calls the individual a schizophrenic, that would be:

<table>
<thead>
<tr>
<th>Very much devaluing</th>
<th>A little devaluing</th>
<th>Not much devaluing</th>
<th>Not at all devaluing</th>
</tr>
</thead>
</table>

9. If someone calls the individual a person with schizophrenia, that would be:

<table>
<thead>
<tr>
<th>Very much devaluing</th>
<th>A little devaluing</th>
<th>Not much devaluing</th>
<th>Not at all devaluing</th>
</tr>
</thead>
</table>

10. If someone calls the individual a schizophrenia sufferer, that would be:

<table>
<thead>
<tr>
<th>Very much devaluing</th>
<th>A little devaluing</th>
<th>Not much devaluing</th>
<th>Not at all devaluing</th>
</tr>
</thead>
</table>
Appendix IV

Screening Questions

1. When you were in hospital and following your discharge did they ever give you a diagnosis? What was the diagnosis?

2. Did you accept the diagnosis?

3. How long ago was that?
Appendix V

SCAN Questions

All the following questions are followed by asking the patient when for the last time s/he had the feeling or experience in question.

Questions about delusions and hallucinations are to be followed by: Are you quite sure, or could you be mistaken? Is there any natural explanation?

1. Have you been feeling low in spirits recently? How long have you been feeling like this? How much of the time are you really low? When was the last time you usually felt free of this feeling? Are there things that make your mood better or worse? (This last item was added to the SCAN questions).

2. Have you been able to positively enjoy things like taking a walk, working at your hobbies or interests, having a nice meal with friends, winning a game or receiving a compliment? How much of the time are you unable to enjoy things as much as usual? When did you last really enjoy something?

3. Have you lost interest in your work, or your recreations? Have you lost interest in your dress or appearance? How much of the time were you free of these problems? When could you last take your normal interest in things?
4. Have you felt that you have lost energy or vigour? Have you lost a vital spark, as though everything was too much trouble; that you couldn’t bother? How long have you had this feeling? How energetic were you when you last felt normal?

5. Have you felt that life is not worth living and that you would not care if you didn’t wake in the morning? Would you ever wish to have some fatal disease or accident?

6. Have you thought about harming yourself or made an attempt at suicide?

7. Do you tend to blame yourself for something you have done or thought, to feel guilty or ashamed of yourself? What is it that you think you have done wrong? How often do you feel guilty?

8. What is your opinion of yourself compared to other people? Do you seem to feel less confident than they are? In what way?

9. Have you found that your thoughts are much slower? Have you seemed to talk or move more slowly than usual? Have your arms or legs felt heavy?

10. What is your appetite like? How long has it been poor or increased?

11. Has there been any change in your weight? Did you lose or gain? What was the most you gained or lost in a month?
12. Have you had any difficulty or disturbance in sleeping or have you been sleeping too much? Has the quality of your sleep been as good as usual? What time do you usually wake in the morning when you are sleeping normally? Have you been waking much earlier than this?

13. I ask this question of everyone and would like to ask you. Do you ever seem to hear noises or voices when there is nobody about and no ordinary explanation seems possible, or see or feel things other people cannot? What is that like?

14. Do you hear them in your head or mind, or in your ears, or as though coming from outside? How do you explain the voices? Where do they come from? Why do you hear them?

15. Have you had visions or seen things other people couldn’t? Have you seen them with your eyes or in your mind? Were you half-asleep at the time? Did it occur when you were fully awake? Do you think the visions were real?

16. Have you noticed unusual smells that you cannot account for? What is the explanation for it?

17. Have you noticed any other sensation of strange or inexplicable sensations or touch, or temperature, or pain, floating, strange sexual sensations or a crawling sensation under the skin? How do you explain these sensations?
18. Have you had the feeling that something odd is going on that you can not explain? What is it like?

19. Has it seemed that your thoughts are read by other people? Can you describe that?

20. Do your thoughts seem to be loud as though someone standing near you could hear them? What is that like?

21. Does a thought in your mind seem to be repeated over again like an echo? Can you describe it for me?

22. Do there seem to be thoughts in your mind which are not your own? Which seem to come from elsewhere? How do you think they get in your mind?

23. Do your thoughts seem to be somehow public; not private to yourself, so that others can know what you are thinking?

24. Do your thoughts sometimes stop suddenly, so that your mind is a complete blank, although you have not yourself wanted to stop thinking? Can you describe that?

25. Are your thoughts actually taken out or sent out of your mind? Do they actually feel like that? So that they are outside your head? What is it like?

26. Do you feel that your will has been replaced by that of some force or power outside
yourself? Can you describe that? Is it like being a robot or zombie or puppet, controlled from elsewhere, without a will of your own?

27. Do you actually seem to be a different person altogether, because your actions are outside your control? Can you describe that? For example were you made to walk, to run by...

28. Are your thought under the control of...so that you do not recognise your thoughts as your own? Is there any other kind of control for example of your feelings or impulses?

29. Do people seem to talk about you, check up on you to find out where you are, follow you about, or record your movements or photograph you?

30. Do people seem to drop hints meant for you, or say things with double meanings? Do you see messages for yourself in the newspapers or on TV or radio? Can you describe an example?

31. Do you sometimes see coded messages or a special significance in the way objects are arranged, or in colours, or in the way things happen? Can you describe it?

32. Are there people about who are not what they seem? Who are perhaps in disguise? Can you give an example?

33. Do you feel that the appearance of people you know well has changed in ways that
suggest that someone might be impersonating them?

34. Does anyone seem to be trying to harm you? (Trying to poison you or kill you?) Are they particularly singling you out? Does there seem to be a plot or conspiracy behind it? How do you recognise that?

35. Are you loved by someone who does not publicly acknowledge it? Who is it? Was s/he the first to try to begin an affair? What evidence have you had of these advances? Do you try to make contact? In what way?

36. Are you influenced or affected by X-rays or radio waves or machines or anything like that?