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Thesis for the Degree of Doctor of Medicine:

The contributions of knowledge and contact to the stigma of mental illness

by

Dr Peter Byrne MA, MB, MRCPsych

Trinity College Dublin

February 2008.

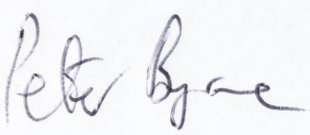
Declaration:

I, Peter Byrne, declare that:

a. this thesis, in whole or in part, has not been submitted to obtain a degree at this or any other University;

b. its contents are entirely my own work, and where studies were carried out in collaboration with others, these have been detailed in the text (Acknowledgements and again in Methods, Chapter 3). In Study One, design, data collection and statistical analyses were shared by Dr David Kane and me: discussions and conclusions from this study (Sections 4.6 to 4.9) are entirely my own work as we have yet to submit the paper to a scientific journal. Study Two was designed by committee (see Acknowledgements and Section 3.2.1) but all differences between this all-Ireland attitude survey and the England and Wales study of Crisp et al (2000) were devised by me: Section 5.5. Data were collected by Lansdowne Market Research, Dublin 2 (see Acknowledgements), but all statistical work presented was carried out by me under the direction of Professor Paul Bebbington with additional statistical advice from Dr Bob Blizard, Head and Senior Lecturer respectively of the Department of Mental Health Sciences, University College London. Study Three was devised solely by me, and I collected 472 / 593 respondents' questionnaires. Dr Brendan Cassidy collected 87 Dublin medical and nursing students', and Dr Paddy Higgins 34 anaesthetists' and theatre nurses' data. I designed and carried out all statistical work for this Study, subsequently published with both colleagues as co-authors.

c. I agree that this thesis, should it be approved by the University, can be subsequently lent for the purposes of study – subject to conditions of acknowledgement.



Dr Peter Byrne.

Summary: the thesis comprises three studies.

Study One is a single face-to-face questionnaire study of **243 patients** with psoriasis and/or arthritis. Because leprosy is an infectious condition, psoriasis is a better model of a stigmatising skin disorder likely to cause embarrassment (anxiety) in people wishing to hide it from the view of others. The challenge was to separate the negative effects of any chronic illness on psychological well-being from its stigma. Diagnoses of psoriasis or psoriatic arthritis (PsA) were confirmed by Consultants, and the control group met international criteria for rheumatoid arthritis (RA). Parameters of disease severity were recorded alongside measures of psychological distress, alcohol use and questions about possible stigma. Univariate analyses compared demographic and disease markers of the three groups, and Mann Whitney U test examined relationships between morbidity and alcohol use. People with psoriasis have similar proportions with low mood to those expected for RA patients, but they have higher anxiety levels. We confirmed (the known) higher levels of alcohol consumption amongst psoriasis patients, but found associations between drinking to excess and increased anxiety and stigma perceptions. 29.7% of the psoriasis group drank more after skin disease onset, despite 34.4% of psoriasis and 29.7% of PsA patients stating alcohol made their psoriasis worse. A cycle of stigma, anxiety and alcohol misuse is proposed to explain this paradox.

Study Two measures the attitude component driving public stigma against people with mental health problems. A public attitude survey, comprising a single face-to-face questionnaire, was devised to define respondents' demographics and their awareness, knowledge and attitudes to six common mental illnesses. Respondents (**n=2,511**) were chosen in the Republic and Northern Ireland, based on the latest available census figures. A fourth variable asked if respondents knew someone who had one or more of the six disorders: "contact". Univariate analyses examined the demographic associations

(respondents' age, gender, marital status, social class and location) for the four parameters, and where significant, logistic regression provided odds ratios; t tests looked for associations between positive attitudes (8 questions for 6 disorders) and each of knowledge and contact. Awareness and good knowledge are high in both jurisdictions (at least 90% and 37% respectively) with the exception of schizophrenia. The public rarely blame people for their illness and have high confidence in treatments for these. The study identified profile *target attitudes* (e.g. high blame for people with eating disorders) but not *target groups*, based on demographics. The two key findings were that neither greater knowledge nor contact was associated with more positive attitudes. Possible explanations for these findings, including the role of perceptions of danger (from people with mental illness) and limitations of this study, are set out.

Study Three examined familiarity with and attitudes to the use of Electroconvulsive Therapy (ECT). **593 students** (medical and nursing) or **professionals** (psychiatrists, psychiatric nurses, anaesthetists and theatre nurses) answered a single, anonymous questionnaire eliciting their responses (levels of agreement or disagreement) to 4 facts and 2 opinions about ECT. Univariate analyses and logistic regression identified associations between vocation and contact (recent exposure to ECT or assistance with its application) with knowledge and attitude. Over one quarter of nurses overestimated ECT's mortality rate and answered two factual statements about consent incorrectly. Contact was associated with more positive attitudes only among medical students and doctors. Though no theatre nurses in this sample had seen ECT in the past year, many nursing students had, but contact had no associations with better attitudes. Membership of the medical group was significantly associated with more knowledge and better attitudes in every instance.

A final chapter integrates the three studies' findings into a coherent theoretical framework, and identifies five broad themes of future stigma research.

The contributions of knowledge and contact to the stigma of mental illness

MD Thesis of Dr Peter Byrne **final revision, February 2008**

Abstract

Drawing on narrative-based, historical, and social scientific perspectives, there is general agreement about the theoretical basis for stigma, and that examining attitudes quantifies aspects of the stigma-discrimination process. Agreeing with a negative attitude is self-stigma in people with the condition and prejudice among unaffected public or professionals. **Study One** (n=243) found high anxiety levels in people with psoriasis, with associations between subjects' perceptions of stigmatisation and anxiety, and these may explain higher the alcohol consumption found in this study and others. Three drivers of attitudes – awareness, experience ("contact") and knowledge – offer potential interventions to reduce mental illness stigma. The largest ever study of Irish public attitudes, **Study Two** (n=2,511), had a number of key findings. There are subgroups of the general population with low awareness and knowledge, but these do not correspond to groups with more negative attitudes. The public has less blaming attitudes and higher confidence in treatments than expected. We failed to confirm the contact hypothesis: that knowing someone who has one of six mental disorders predicts better attitudes to them. Nor does better knowledge equate with more positive attitudes. There are target attitudes (negative stereotypes) for each disorder that can form the basis of future interventions, for example perceptions of danger in schizophrenia and the addictions. **Study Three** (n=593) identified professional background, rather than knowledge or experience, that predicted adverse attitudes to ECT among staff and students. Contact and education do not impact upon nurses' attitudes. Taken together, the three studies confirm the substantial challenge of stigma and how perceptions drive negative attitudes – even in people with good knowledge. Findings fail to support the medical model of anti-stigma work or a generic strategy of increasing contact. Five lessons to advance stigma research are proposed, and new strategies should be complemented by better models for measuring actual behaviour.

CONTENTS

Abbreviations used in the text

Investigators in Study One: PdB, DK & PB; in Study Three: BC, PH & PB.

ACR American College of Rheumatology

AD Antidepressant medication

ANOVA Analysis of variance: statistical test

APA America Psychiatric Association

ASI Alzheimer's Society of Ireland (all-Ireland carers' organisation)

BDI Beck Depression Inventory (scale to measure depression)

CIS Clinical Interview Scale

CMHT Community mental health team: interdisciplinary health professionals

DSM4 Diagnostic and Statistical Manual for the diagnosis of psychiatric disease, 4th Ed

ECT Electroconvulsive Therapy, described elsewhere as electroshock therapy

EMIC the Explanatory Model Interview Catalogue: semi-structured interview

GHQ General Health Questionnaire (self-rating scale)

HADS Hospital Anxiety and Depression Scale (self-rating scale)

HAQ Health Arthritis Questionnaire (scale)

ICD10 International Classification of Disease, 10th Edition: manual for the diagnosis of psychiatric disease, published by the World Health Association

ICP Irish College of Psychiatry

IHD Ischaemic heart disease

MHL Mental health literacy

MLT Modified labelling theory (of Bruce Link)

MRCPsych Member of the Royal College of Psychiatrists

MTX Methotrexate medication for the treatment of arthritis and psoriasis

NI Northern Ireland: the six counties currently part of the UK

NIMBY Not-in-my-back-yard: community opposition to the locating of certain facilities (e.g. psychiatric group homes, clinics) in their locality

NS Not significant

NSAID Non-steroidal antiinflammatory drugs: painkillers (used in arthritis)

OMI Opinions about Mental Illness (scale)

ONS Office of national Statistics

OR Odds ratio

PDI Psoriasis Disability Index (scale)

PLSI Psoriasis Life Stress Index (scale)

PsA Psoriatic arthritis

PSE Present State Examination: a structured diagnostic clinical interview to determine a person's ICD10 psychiatric diagnosis

PTT Pull-themselves-together (attitudes): a belief that people with the disorder could control it or make it better by a show of will power

QoL Quality of Life (scales): used to quantify the subjective experiences of patients with physical and / or psychological disorders

RCP Royal College of Psychiatrists in the UK and Ireland

RoI Republic of Ireland

RTE Radio Telifis Eireann: the RoI state television company

SD Social distance

SEG Socio-economic Group: higher SEG denotes higher income

TSD Total Social Distance

UDP Unique Distancing Point, opposite to the concept of USP (unique selling point)

UK United Kingdom

US United States

WHO World Health Organisation

Acknowledgements

This doctorate was directly supervised by Professor Paul Bebbington, Head of Department of Mental Health Sciences at University College London. From the outset, Professor Bebbington encouraged me to read around the topic, and as a result, Chapter One evolved into an extensive review of diverse directions in anti-stigma research (already published in an abridged form as Chapter 11 in Core Psychiatry – Edited by P Wright, J Stern and M Phelan, published by Elsevier Saunders, London 2005). All statistical advice and supervision was supplied by my departmental colleague Dr Bob Blizard, Royal Free & University College Medical School. Professor Brian Lawlor supervised on behalf of Trinity College Dublin. **Study One** was carried out with Dr David Kane (DK), currently Consultant Rheumatologist at Tallaght University Hospital and then elective medical student, now *Dr* Pepin deBondt (PdB). **Study Two** was developed by the Management Committee of the Royal College of Psychiatrists' Changing Minds campaign, of which I was a member. I applied the knowledge to the question set that I had gained from initial study of the literature (Byrne, 1997). The Public Education Committee (PEC) of the ICP, which I chaired in 1999, revised this question set, and commissioned the survey. Funding is set out in Chapter Three. **Study Three** was carried out Brendan Cassidy (BC), Consultant Psychiatrist, St John of God Hospital, Stillorgan, County Dublin and Patrick Higgins (PH), Consultant Anaesthetist, St James Hospital, Dublin 8. This study has been published in the Journal of ECT 2006; volume 22: p 133-38. Finally, historical and hard-to-locate references in this thesis would not have been possible without enthusiastic assistance from two librarians: Sean Love at Cork University Hospital, where I began to research this area in 1996, and Christine Stephens of the Aubrey Keep Centre, Hornchurch, Essex, where I worked until 2007.

February 29, 2008.

Chapter One: Introduction

This chapter establishes the importance of stigma and discrimination to people with mental health problems, and outlines its theoretical roots. Beginning with current constructs, it traces their historical background, service users' perspectives, and the contributions of the social sciences. It concludes with consensus statements and identifies how attitudinal components of the stigmatisation process can be measured.

Section 1.1: Current concepts of stigma

1.1.1 The dictionary definition sets out stigma as "a mark of disgrace or discredit which sets a person aside from others" (Byrne, 1997). More pertinent to mental illness stigma is that it is a **prejudice** based on **stereotypes** resulting in **discrimination** (Corrigan et al, 2003). Erving Goffman (see Section 1.4) did not discover stigma forty years ago, rather he appropriated the term. Through examination of a range of social situations where individuals were stigmatised, Goffman (1963) documented a variety of negative stereotypes which drive stigma. Agreement with the stereotype is a prejudice (attitude) among stigmatisers ("they are no good"), but similar agreement by the stigmatised is self-stigma ("I am no good"). Both sets of attitudes will be explored in Studies Two and One respectively. Link and Phelan (2001) have set out the current sociological context for understanding stigma. Stigma exists when four components converge. These are (1) the distinguishing and labelling of differences (2) the association of some human differences with negative attributes (3) the separation of "us" from "them" and (4) status loss and discrimination. All theoretical approaches (narrative-based, social scientific and attitudinal) have divided the world into good and bad. Bad people are stigmatisers, holders of prejudicial belief systems and / or people who use their positions to mark and maintain stigma. But Link and Phelan (2001) contest this: "by itself the standard model that asks 'what-makes-person-A-discriminate-against-person-B' is inadequate for explaining the full consequences of stigma processes". Discrimination need not

be overt or conscious, and frequently it is the loss of status (by the recipient) that is the source of other (social, economic, political) discriminations. For these to occur, the additional dimension of **power** must exist in the relationship (Link and Phelan, 2001). They conclude by asking four questions of the in-group / potential stigmatisers: (1) do they have the power to ensure that the human difference they recognise is broadly identified in the culture? (2) do they have the power to make sure the culture accepts the stereotypes they connect to labelled differences? (3) do they have the power to separate us from them, and to make the designation stick? (4) do they control access to education, employment, health care, and housing? If the answers are yes, we can expect stigma to result. If the answer to these questions is no, "what we generally mean by stigma would not exist" (Link and Phelan, 2001).

1.1.2 The effects of stigma are set out below, but Corrigan and Watson (2003) have addressed the central question as to *why* humans stigmatise. They argue that a motivational model, called *system justification*, helps individuals make sense of economic and political differences. Using this model, aberrant behaviour (for example the symptoms of a mental illness) is marked out as different, and a prejudice is triggered which is a combination of both the impact of the behaviour itself and any label ("he's crazy" or "he must be a schizophrenic") attached to it. Corrigan et al (2003) make the point that although the stereotypes of people with mental illness are substantially inaccurate, there may be a "kernel of truth" which perpetuates both the stereotype and the prejudice: see Section 1.6.3. According to the *system justification* paradigm, both the stereotypes and the prejudice develop to confirm the historic, economic, social, or political system: other explanations would contradict the *just world hypothesis* or invoke discomfort in individuals who see themselves as fair-minded and free of prejudice (Corrigan and Watson, 2003). These ideas are paralleled by social psychological theories that people stigmatise others (a) to enhance their own self-esteem (b) to enhance their social identity or (c) to justify a

particular social, economic or political structure (Crocker et al, 1989). Thus far, most theoretical work has addressed the first two components of stigma (prejudice and stereotypes), but the reality for people "at the rough end" is what *happens* to them. Discrimination is the behavioural consequence of prejudice and stigma (Corrigan, 1998), and the Section 1.2 takes this as its starting point. For excluded people, stigma can result in avoidance by others, reduced social networks, negative economic sanctions, or a language of exclusion. Each of these is difficult to measure as discrimination, though that is clearly the end result. Chapter One's aim in looking beyond discrimination (Section 1.2), through stereotypes (Sections 1.3 and 1.4) and the nature of prejudice (Sections 1.5 and 1.6), is echoed within T S Eliot's words: "We shall not cease from exploration, and the end of our exploration will be to arrive where we started, and know the place for the first time".

Section 1.2: Discrimination: service users' perspectives

1.2.1 For many, even the term *stigma* does not usefully describe the range of negative experiences consequent to a psychiatric diagnosis (Sayce, 2000). Largely absent from the pre-1990s psychiatric literature on stigma were direct first person narratives of the effects of stigma (Byrne, 1997 & 2001). Shaw (1998) recalls the reaction to her book about her postnatal depression: "how can we believe this person's account to be credible when she says herself that she was suffering from severe depression at the time?" Because there is no prototype service user or universal set of experiences, analyses of first person accounts share the same limitations as the media studies' approach (Section 1.3.4). It is difficult to categorise these experiences into a single pathway: even if we isolate the five experiences of shame, self-stigma, status loss, loss of social networks, and economic consequences (the first five rows of Table 1.1), the variation between (and within) individuals, diagnoses, settings, cultures and sub-cultures is too diverse to quantify. Nor can we separate cause from effect in the last three of these five experiences, and there are

too many uncertainties to provide empirical measures: (Table 1.1). Discrimination is a relatively rare event, and one which can be concealed, perhaps deliberately, by the stigmatiser, and the recipient of stigma may be unaware it has occurred. Thus the *discrimination only* way of measuring stigma will undervalue it: (Table 1.1). This is not to dismiss first person narratives from consideration, and many publications elucidate many aspects of stigma-discrimination due to mental illness: (Box 1.1). These seven books (Box 1.1) are written entirely or jointly by service uses and therefore serve as a far better introduction to, and explanation of, stigma and discrimination than the scientific literature. All are written in an accessible style and have achieved broad readerships: in general, their focus is discrimination, rather than stigma.

Box 1.1 Publications which describe stigma from users' perspectives

Patrick Corrigan and Robert Lundin. *Don't Call Me Nuts: coping with the stigma of mental illness*, Chicago: Recovery Press, 2001.

T. Heller, J. Reynolds, and R. Gomm. *Mental Health Matters: A Reader*, London: Macmillan, 1996.

J Nunes and S Simmie. *Beyond Crazy: Journeys Through Mental Illness*. Toronto: McClelland and Stewart Ltd. 2002.

J. Read and J. Reynolds. *Speaking Our Minds - an Anthology*, London: MacMillan Press Ltd, 1996.

Liz Sayce. *From Psychiatric Patient To Citizen*. London: MacMillan Press Ltd, 2000.

Anthony Scott. *Is that me? My life with schizophrenia*. Dublin: A & A Farmer, 2002.

Otto Wahl. *Telling Is Risky Business - Mental Health Consumers Confront Stigma*, New Brunswick: Rutger's University Press, 1999.

Table 1.1: Problems encountered in measuring stigma-discrimination due to mental illness

TEN ASPECTS	RESEARCH METHODS	POTENTIAL CRITICISMS OF THIS RESEARCH	Net measures of stigma-discrimination
Shame of MI diagnosis	Interviews with symptomatic people who do not present	Other cultural confounders of delayed or non presentation Is this lack of awareness of mental illness or of its stigma?	↓↓
Self-stigmatisation	Interviews with service users and people who do not present to services	Prospective studies needed: assumption that reduced self-esteem is driven mainly by psychiatric illness (the effects of label or illness?), and that stigma is the "second illness".	Unknown factors
Loss of status due to label (NOT the illness)	Surveys of service users and family members	Effort after meaning, stress and blaming (among relatives), described by professionals as "expressed emotion"	↑↑
Effects on social networks	Interviews with service users	Prospective studies needed: difficult to separate out processes of illness, its treatment and recovery from other social issues	↓↓
Markers of economic losses	Employment & income levels	Confounders: the direct effects of psychiatric illness, lifestyle choices, the economic effects of chronic illness and isolation	Unknown factors
Overt discrimination	Surveys of service users	Low response rates: see Section 1.2.2 Bias in responders: "active" service users more likely to reply Neglects latent / indirect / institutional discrimination Separation of effects of mental illness from effects of the label	Unknown factors ↑↑ ↓↓ Unknown factors
Institutional discrimination	Surveys of the powerful & opinion formers	Many "stigmatisers" (e.g. landlords) are not a cohesive group Socially desirable answers from respondents with vested interest Some institutions (e.g. benefits agencies) refuse to participate Which level on the institution's hierarchy to survey	Unknown factors ↓↓ ↓↓ Unknown factors
Process of discrimination	Field studies	Volunteers may show social desirability both in the study, and towards other volunteers "acting" as people with mental illness Field studies seldom recreate group dynamics Can subjects' behaviour predict real world responses?	↓↓ ↓↓ Unknown factors
Indirect discrimination	Physical health of service users	Confounders: the direct effects of psychiatric illness, lifestyle choices, the economic effects of chronic illness, social factors	Unknown factors
Stigma during psychiatric patient career	Treatment discontinuations / Involuntary admissions rates	Too many confounders: "insight" as a measure of agreement between patient and clinician, sociodemographic confounders	Unknown factors

↓↓ stigma underestimated ↑↑ stigma overestimated

1.2.2 Service users' surveys measure discrimination by asking people directly about their experiences (Read and Baker, 1996; Mental Health Foundation, 2000). These have had very low response rates (31.1% and 13% respectively), and are therefore open to the charge of overreporting acts of discrimination by a self-selected group: (Table 1.1). That said, their findings cannot be ignored. Read and Baker (1996) found that 47% (of service users) had been abused or harassed in public, 26% had moved home because of harassment, with physical assault in 14%. Mental Health Foundation (2000) reported discrimination in the workplace (47%), employment (37%), from friends (26%), and access to housing (10%). Wahl (1999b) surveyed 1,301 US consumers (service users), finding that clear majorities had stigma fears/experiences, but discrimination events were relatively less frequent: for example, refused health insurance (40%) or a job (32%) following disclosure of mental illness. Berzins et al (2003) report that harassment (predominantly verbal) is experienced at least twice as frequently by people with mental health problems as by a control population. Thompson and Thompson (1997) provide a comprehensive list of the settings of discrimination against service users, admitting they have only "scratched the surface": one finding (reminiscent of the racial discrimination literature) is that the nature of discrimination changes as new laws / quotas / guidelines are enforced. What is striking about the "discrimination only" approach is that in all cases but one, measures of stigma will *underreport* the phenomenon: (Table 1.1).

1.2.3 Sayce (2000) criticises three theoretical approaches in this area: brain disease (medical), libertarian (human rights), and individual growth models. She concludes by supporting a fourth model: "of all the models currently adopted to tackle 'stigma' (her inverted commas) or discrimination, the one that holds the most promise is the disability inclusion model. It does not contain within it the seeds of discriminatory ideas. It neither removes all responsibility from user / survivors nor makes them responsible for being 'mentally ill'". Corrigan and Penn (1997) examined the disease versus discrimination paradigm of stigma, outlining ways in which the strict medical-

scientific view of mental disorders has too narrow a focus: "perhaps most foreign to the disease perspective is the notion introduced by the discrimination model regarding political and economic forces affecting the course and outcome of severe mental illness". More recently, and writing from a user's perspective, Rose (2002) argues that service users can utilise some aspects of the medical model ("fragmentation has advantages") provided they resist psychiatry's quasi scientific language of incompetence and insight. One of the limitations of a discrimination model may be that only direct, overt, or blatant discrimination may be considered. This is important in Western societies where anti-discrimination laws (for the stigmata of race or sexual preferences) have unintended consequences in driving discrimination underground. In relation to mental illness stigma, we can identify key stigma components in the health services: indirect discrimination, value judgements, prejudice, and exclusion. Levenson and Oldbrisch (1993) measured medical staff opinions as to the suitability of people with schizophrenia for organ transplantation, given the rationing due to high costs of these procedures. They report that "active schizophrenia" (sic) is an *absolute* contraindication to transplant in 92% cardiac, 67% liver & 73% renal units; when the condition is described as "controlled schizophrenia", staff believe this to be either an absolute or relative contraindication: 85%, 80% and 68% respectively. Phipps (1997) has described 11 years of cardiac transplantation (n=706) in Montreal: 28 people were denied this procedure on "psychiatric grounds". These included a history of drug or alcohol misuse (7 people), non-compliance (3), multiple suicide attempts (2), unrealistic expectations (2), antisocial (3) and borderline personality disorder (2) (Phipps, 1997). In a prospective study of 73 subjects with alcoholic liver disease, (Yates et al, 1998) failed to find any relationship between personality disorder diagnosis and relapse in alcohol misuse after transplant. Although not originally presented as such, the former two studies indicate discrimination by the medical profession against "psychiatric" people.

1.2.4 In summary then, the discrimination paradigm has advantages of identifying the real effects of the stigma of mental illness on individuals. Where there is disadvantage, it is disadvantage due both to mental health problems and to the effects of the label / diagnosis (stigma as "the second illness": Schulze and Angermeyer, 2003). It is a practical, radical, nonmedical, empowering approach, and, regardless of the quality of the information one collects on discrimination, this can be presented directly to decision-makers. It neglects however the individualisation and internalisation of stigma, self-stigma (Table 1.1). Further, if we define overt discrimination as enacted prejudice, we also need a theoretical framework to understand the effects of unenacted prejudice. While many of us hold a variety of prejudices (sexist, homophobic, ageist etc.) we "hold back" from their overt expression. But there are also consequences of unspoken prejudice (avoidance, covert discrimination in favour of "normal" others), and Aviram and Segal (1973) identified seven separate mechanisms by which Californian institutions excluded people with mental illness, thereby moving them from the "back wards to back alleys". Discrimination research identifies some of the *what?*, the *where?* and *to whom?* questions, but it neglects both the *how?* the *why?* and the *how much*? One cannot study stigma without studying discrimination, but addressing discrimination alone will not answer the last two questions, or uncover hidden discriminations (*where else*? as described for health service discrimination above). To develop these ideas, *second hand accounts* of stigma-discrimination are discussed in Section 1.3.

Section 1.3 History, social history, anthropology and media studies

1.3.1 Although most texts about the stigma of mental illness usually begin with the seminal work of Goffman (1963), Fabrega (1990) charts its historical development across many cultures. People with mental disorders may behave unusually, and across many cultures that behaviour has been marked as different and undesirable. Fabrega (1990) describes psychiatric illness as a "complex and abstract social

object: it is a condition conceptualised as having negative social meanings and elicits distinctive attitudes and dispositions that have historical roots in earlier political, economic, cultural, social and other conditions". Ancient Israel gave "normal legal status" to individuals who had bouts of madness (especially if they were economically prosperous – see *Power* discussion of Section 1.1.1), but treated the insane as incompetent. For the latter group, marriages were declared invalid, they could be defamed without consequence to the aggressor, and were frequently stoned in the street (Rosen, 1968). In the Hellenistic medical tradition, *melancholia, mania, lycanthropy* and *hysteria* (what we now call mental disorders) were not deemed especially different from other (medical) diseases (Fabrega, 1990).

1.3.2 Social historians, notably the late Roy Porter (1991 & 2002), have documented the historical mistreatment of people with mental illness based on fashionable but now discredited contemporaneous theories. Beyond these, there have been forced sterilisations in the US and Europe, and people with mental disabilities were part of Nazi genocide (Hinshaw, 2000). In the light of Porter's frequent use of first person narratives, his work parallels service users' accounts (Section 1.2 and Box 1.1). Porter (1991) quotes many narratives at length:

- I mean, that I was never told, such and such things we are going to do; we think it advisable to administer such and such medicine, in this or that manner; I was never asked Do you want anything? Do you wish for, prefer anything? Have you any objection to this or that?...I was not however once addressed by argument, expostulation or persuasion. The persons round me consulted, directed, chose, ordered, and force was the unica and ultima ratio applied to me.

John T Perceval ***(1838)*** *A Narrative of the Treatment Received by a Gentleman During a Mental Derangement. Reprinted 1974; New York: Morrow Paperback Editions.* Cited by Porter (1991) in Chapter 11, page 247.

- Yet this interference with what I deemed my rights proved to be the first step in the general overruling of them by tactless attendants and, in particular, by a certain assistant

physician... My attendants were incapable of understanding the operations of my mind, and what they could not understand, they would seldom tolerate... (they) would drive a sane man to violence.

Clifford Beers ***(1923)*** *A Mind That Found Itself. New York: Doubleday.* Cited by Porter (1991) in Chapter 4, page 111; and by Porter (2002) in Chapter 7, page 169.

- Every month a group of women whom we called "The Ladies" arrived to visit us... and some of us uncharitably despised them, for they did not seem to be able to make up their minds whether we were deaf or dumb or mentally defective or all three, so when they spoke they moved their lips with exaggerated care, and their vocabulary was simplest, in case we did not understand. Sometimes they gestured as if we were foreigners and they were visitors to our land who needed to try our language.

Janet Frame (1961) *Faces in the Water.* London: The Women's Press. Cited by Porter (2002) in Chapter 10, page 232.

1.3.3 Alongside narrative accounts, anthropologists, for example Littlewood (1986) and Weiss et al (2001), have documented the many ways in which various cultures continue to set people with mental illness aside from the rest of their society, and reconstruct cultural norms to reinforce others' inferior status. Accepting cultural differences, there are frequent points of contact between societies: strong rejecting beliefs about marriage (to a stigmatised person) were almost identical in two samples from London and Bangalore (Weiss et al, 2001). Weiss et al (1992) have used a semi-structured interview (the Explanatory Model Interview Catalogue, EMIC) to examine leprosy, which they describe as "the archetypal stigmatising medical illness". They draw an observer-based distinction between an insider's perspective (emic) and the outsider's (etic), usually based on professional ideology. They interviewed people recently diagnosed with leprosy, and compared findings with vitiligo patients (a skin condition far less stigmatising than leprosy) and controls. Quantitative results included depression diagnoses in 50%, 37% and 8% respectively. Their hypothesis was proven that in the early stages of leprosy, its cultural meanings and the emotional implications of these outweigh the burden of

somatic symptoms. They conclude by speculating that the information obtained by the EMIC will be useful in predicting key clinical variables of help-seeking, compliance and future treatment drop-outs (Weiss et al, 1992). The evolutionary origins of stigmatisation have been explored by Kurzban and Leary (2001). Although their theoretical arguments have a different focus, they parallel anthropological work and the theoretical construct of Link and Phelan (2001) in Section 1.1.1: relationships that matter are about power.

1.3.4 Another approach to understanding stigma is through the media. Clausen (1981) wrote that: "a stigma exists, then, in the media, and one cannot help but be concerned lest it come to be again manifest more widely in the general population". For some, the media are ***the*** cause of mental illness stigma, yet this is impossible to prove. Various media produce snapshots of stigma, and these are an interesting way to reveal aspects of stigma (Byrne, 2000 & 2001). Wober (1985) reported that 17% of US prime time programmes involve some significant depiction or theme of mental illness. Their currency is the stereotype, at its most extreme in media representations of the psychokiller (Byrne, 1998). The movie psychokiller, with (usually) *his* roots in Victorian horror and melodrama, is both mad and bad, and frequently returns to familiar surroundings to effect a brutal revenge for real or imagined wrongs (Byrne, 1998). The rationale for mad-bad demonisation is rooted in the Enlightenment. In 1793, Philippe Pinel "struck off the chains from his charges" (Porter, 2002) in the asylums of Paris, yet it was Pinel who defined madness thus:

- Of all the afflictions to which human nature is subject, the loss of reason is at once the most calamitous and interesting. Deprived of this faculty, by which a man is principally distinguished from the beasts that perish, the human form is frequently the most remarkable attribute that he retains of his proud distinction. His character, as an individual of the species is always perverted, sometimes annihilated. His thoughts and actions are diverted from their usual and natural course. The chain which connected his ideas in just

series and mutual subserviency is dissevered. His feelings for himself and others are new and uncommon. His attachments are converted into aversions, his love into hatred.

*Phillippe Pinel (**1806**) A Treatise on Insanity. London: Cadell and Davies.* Cited by Porter (1991) in Chapter 1, page 12.

1.3.5 Though undoubtedly progressive for, and of, its time, Pinel demonstrates Cartesian dualism in dividing the world into good / evil, sane / insane, human (in appearance only) / inhuman (by nature), moral / immoral, love / hate etc. It is this division, crystallised by Robert Louis Stevenson (1885) in *The Strange Case of Dr Jekyll and Mr Hyde*, that drives the psychokiller stereotype (Byrne, 1998). Townsend (1979) compares the evidence to support mental illness stereotypes with that supporting the existence of ethnic stereotypes, and finds many parallels between the two. It is important to note that recognition of a stereotype (ethnic, racist, ageist, sexist etc.) can be a neutral finding, in that recognition does not imply agreement with the stereotype. Banner headlines and movie psychokillers do not in themselves prove that there is a stigma of mental illness: they prove that the writer / producer is at least aware that society recognises the motifs and endorses them as having some basis in reality. Three other stereotypes of mental illness are the pathetic mad, the comedic and the weak (Byrne, 1997). Media studies, like first-person narratives, social historians and anthropologists, point the way towards aspects of prejudice.

Section 1.4 Sociological perspectives

1.4.1 Erving Goffman (1963) stimulated a resurgence of interest in all types of stigma from a predominantly sociological perspective. For Goffman, a stigmatised person:

- is disqualified from full social acceptance (p9)
- is a blemished person, ritually polluted, to be avoided especially in public places (p11)
- has a discrepancy (stigma) between his actual social identity and his virtual social identity ... that virtual social identity is formed by certain expectations and normative expectations (by others about the stranger) (p12)

- has a character blemish... (and) we construct an ideology to explain difference using language (p15)
- can transform himself only into someone who has corrected a blemish, or throws himself at the mastery of other activities (p17) ... (or) uses stigma for secondary gain: all ills are through this (stigma) (p21) ... (or) seeks sympathetic others who share his stigma, resigning himself to a half-world (p31) ... (or) seeks the wise (p41).

Goffman (1963) draws on the parallels of prostitutes who seek the company of Bohemian artists, actors and writers in defining *the wise* as "persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatised and sympathetic to it... Wise persons are the marginal men before whom the individual need feel no shame nor exert self-control, knowing that in spite of his failing he will be seen as the ordinary other" (p41). He cites examples of people who are wise through professional relationships "gentile employees in Jewish delicatessens... straight bartenders in homosexual bars ... nurses and physical therapists" or by personal contact "loyal spouse of the mental patient, daughter of the ex-con, friend of the blind" (p42). He defines this latter group as persons with a *courtesy stigma* (i.e. stigma by association), but cautions that: "the person with a courtesy stigma can in fact make both the stigmatised and the normal uncomfortable: by always being ready to carry a burden that is not really theirs, they can confront everyone else with too much morality" (p44). From the perspective of the in-group, we do not wish to define ourselves as prejudiced: we idealise our responses ("some of my best friends have mental illness") and seek to minimise acts of discrimination and omissions ("I'd like to hire someone with schizophrenia, but the job would be too stressful for him"). The coping mechanisms listed above by Goffman (denial, displacement, projection and search for sympathetic others) all make stigma harder to find and to measure. Reactions to mental illness by people who become ill are exactly the same as those found in general public samples (who do not), namely "denial, isolation and insulation of mental illness" (Cumming and Cumming, 1957A).

The (well-meaning) efforts of the wise to counter stigma by denying its existence, or forcing upon others idealised images of the stigmatised that provoke rebound. Three possible groups then are the in-group, the stigmatised and the wise: **Figure 1.1:**

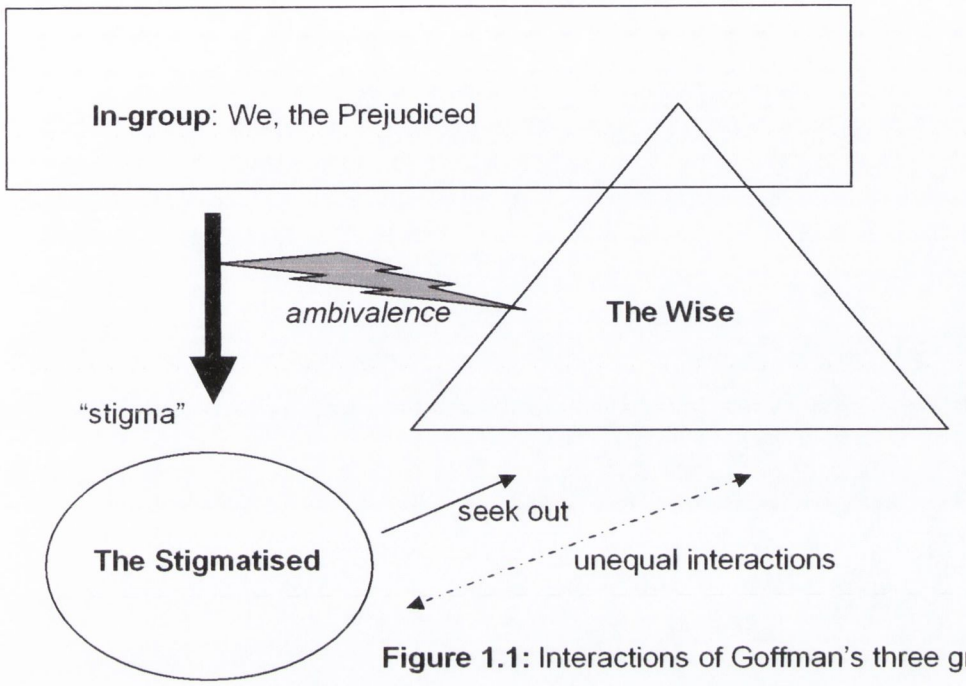


Figure 1.1: Interactions of Goffman's three groups

Taking the example of a psychiatrist who has depression (Shooter, 1996), he is at different times, a member of all three groups of Figure 1.1. Goffman did not wish to confine attention to the marks of stigma, itself something that increases stigma, and called for a "**language of relationships, not attributes**." Thus while we can identify *them*, *us* the in-between *wise* (Figure 1.1), the key foci here are the interactions between groups (the arrows), not the groups in themselves

1.4.2 Another influential sociologist, Thomas Scheff, wrote specifically about people with mental illness: for Scheff, the process of deviance and its labelling overrode other concerns (Scheff 1966). Scheff rejected the psychiatric "slogan" that mental disorders were an illness like any other, arguing that none of the four components of the medical model (cause, lesion, symptoms and outcome) applied to Psychiatry (Scheff, 1974). Labelling Theory assumed societal conceptions of mental illness would cause deviant behaviour to be so labelled; others' reactions to the behaviour

were based on these conceptions; and the person then adopted the role of "mental illness". Scheff (1966) believed that "labelled deviants may be rewarded for playing the stereotyped role... and are punished when they attempt to return to conventional roles". He concluded: "when the individual internalises this role, incorporating it as a central identity, chronic mental illness is the consequence" (Scheff 1966; quoted by Link et al, 1989). Scheff (1966) used some interesting data to support his theory: one example is the finding (still replicated today) that being male, poor, and from an ethnic minority are all predictive of involuntary committal to a mental hospital. Scheff (1966) cited these three predictors of committal to promote labelling theory, but findings from the contemporary literature on mental illness stigma better explain them. There is evidence that (1) men are more likely to be stigmatised than women (Farina, 1981; Norman and Malla, 1983), (2) a greater power differential (e.g. economic) between stigmatiser and stigmatised makes stigma-discrimination more likely (Link and Phelan, 2001) and (3) unspoken racial prejudice may accompany other prejudices (Townsend, 1979 & Bhugra et al, 2001). Recent US research identifies social factors inherent in the hospitalisation process: black Americans are less likely to have been outpatients prior to committal, and that committal is more likely to be involuntary and for behavioural disturbances, rather than voluntary and for symptoms, as with white controls (Sohler et al, 2004). This evidence undermines Scheff's assumptions. Scheff's Labelling Theory has been cited as implying that there is no mental illness, but he later argued that he did not wish to replace Psychiatry, and revised his belief that societal reaction was the *most important single cause* of mental illness, but accounted for 5-10% of cases (Scheff, 1975).

1.4.3 Opposition to Scheff's Labelling Theory, led principally by Gove (1975 & 1979), was fierce and sustained across sociological journals. Gove (1975) challenged the empirical basis for the theory and its "simplicity". Although he conceded that Scheff's original position (*there is no mental illness*) might be argued in the 1950s, advances

in psychiatry had made that construct unsustainable (Gove, 1975). He did accept that "the societal reaction to mental illness is clearly inadequate and presents a very distorted image of mental illness". Gove (1975), like Scheff, played down the role of stigma: "in the area of mental illness, the processes associated with hospitalisation do not cause others to view the individual as deviant (they already do so) but instead often redefine the deviance in a fairly positive way". Over the years, many researchers continued to challenge Scheff's Labelling Theory. Kirk (1974) presented vignettes to 864 US College students, and found it was behaviour (and not labelling) that determines the attitudes of respondents. Lehmann et al (1976) reported "no evidence" that labelling elicited rejection of videotaped behaviour among 90 US College students. These two studies seem at variance with a previous study (Phillips, 1963) where rejection of "mental illness behaviour" increased from those who sought no help to those who consulted a physician, a psychiatrist and (most rejecting of all) mental hospital admission. Failure to resolve this issue indicated that the real casualty of Scheff's Labelling Theory, and the acrimonious debate that surrounded it, was rigorous, empirical stigma research.

1.4.4 A notable exception was the sustained output from sociologist Bruce Link (Link et al, 1982, 1987, 1989, 1991, 1997, 1999a & 1999b) which attempted to restore the consensus. Link began with the assertion that some writers (listed above) played down the salience of social factors such as stigma to win their arguments against Scheff about labelling theory (Link et al, 1989). Link also acknowledged the work of Peggy Thoits (1985) who criticised Scheff, not for his absolutist statements, but for ignoring the phenomenon of "private self-labelling". She drew on the experience of voluntary admissions to mental hospitals and the observation that *social control* is mostly self-control. Her perspective was the examination of identity-relevant stressors from the inside out, specifically role identities: "self-conceptions based on enduring, normative, reciprocal relationships with other people" (Thoits, 1985 &

1991). Link's M*odified Labelling Theory* (MLT) proposed an alteration to the intermediate stage in Scheff's labelling theory: it was not the response of others, but rather the response of the labelled individual that predicted future vulnerability to relapse and low self-esteem (Link et al, 1989). MLT allowed for multiple relapses in severe mental illness where the person was unaware of the label (psychiatrists would say *insightless* about the diagnosis) and accepted circumstances where psychopathology alone led to negative outcomes. Inherent in MLT were three possible "coping orientations": secrecy, educating others, and avoidance of situations where rejection might occur (Link et al, 1991). One of the assumptions of MLT is that all three coping orientations make the consequences of stigma worse (Link et al, 1991 & 1997), and this will be examined in Section 2.2.

Section 1.5 The application of psychological principles

1.5.1 Explicit in the work of Thoits (1985, 1991) and implied by Link, has been the concept of self-esteem. Whatever the type of social sanction (discrimination, devaluation, avoidance), its effects on the individual will be mediated along the final common pathway of low self-esteem. Rosenhan (1973) drew on the work of both Scheff and Goffman in his study on the admission of eight pseudopatients (Rosenhan himself, 4 other psychologists, a psychiatrist, a painter and a housewife) to a psychiatric hospital with rehearsed false symptoms of acute psychosis (each stated they had heard the word "thud" in a manner similar to auditory hallucination). Staff were not aware of the study. Once admitted, the 8 pseudopatients answered all questions truthfully, and behaved as they would normally have done. Ward staff continued to regard their behaviour as indicative of paranoid schizophrenia: meeting as a group, excessive note-taking and nervousness of their environment (most pseudopatients had not seen ward conditions prior to the study). While fellow patients judged the pseudopatients as fit and well, no staff member formed this view: "once the impression had been formed that the patient is schizophrenic, the

expectation is that he will continue to be schizophrenic" (Rosenhan, 1973). A separate though less quoted finding was the low frequency of staff-patient interaction (echoes of *them* and *us*), high frequency of pseudopatient-initiated contact where the staff member moved away, without answering a simple question (Rosenhan, 1973). The lack of social interaction and the consequent *depersonalisation* of "patients" are the combination of common prejudices and the hierarchical structure of psychiatric institutions, where medication serves only to "convince staff that treatment is being conducted and further patient contact is not necessary" (Rosenhan, 1973).

1.5.2 Social psychology recognises that all behaviour takes place within a social context, and that even when alone, our actions and inaction are influenced by others. Because stigma is a social construct, we must distinguish between interpersonal and intergroup processes: there are similarities, but the two processes need to be studied within separate frameworks. From the perspective of the target of stigmatisation as well as the stigmatiser, the distinctions around personal and social identity determine the nature and degree of interactions. Crocker et al (1998) have reviewed social stigma, of which mental illness is one example. One aspect, stereotype threat, occurs where a stigmatised person is aware both of the negative stereotypes (about their status / condition) and that their behaviour will be judged on these grounds. "Several aspects of the self-concept are at risk for the stereotype-threatened individual: both the personal self-concept and the collective self-concept (or social identity) are threatened, and both these aspects may be threatened at both the private (what one privately believes to be true) and the public (what one assumes others believe to be true) level" (Crocker et al, 1998). They conclude that for stigmatisers, "stigma is about sustaining the belief that I am and we are good (or at least better than <u>they</u> are), maintaining our belief that we are just, fair and deserving". Accepting the importance of social scientific contributions in asking the right questions, one criticism is that sociological, anthropological, psychological, media and historical perspectives use only qualitative measures – but they provide the basis for empirical measures.

Section 1.6 Integrated model of stigma: what aspects can be measured?

The aim of this chapter has been to integrate the multitude of theoretical approaches to understanding prejudice-stigma-discrimination as it applies to mental health in order to quantify potential stigma measures in as rigorous a manner as possible.

1.6.1 Firstly, long before the institution of psychiatry, there was stigma – individuals were devalued, mocked, abused and / or avoided based on their behaviour – and the degree of ostracism was a function of that society's belief systems. Secondly, Psychiatry provided the labels ("diagnoses") and the settings (asylum, clinic, group home, etc) which explained and contained aberrant behaviours ("symptoms") and made recognition easier. Stigma has a bidirectional relationship with the settings of Psychiatry in that one continuously downgrades the other. Some physical psychiatric treatments are stigmatising in a literal sense: the extrapyramidal side effects of typical neuroleptic medications, or the sedating effects of some anxiolytics, most antipsychotics and older antidepressants. Depending on one's perspective (agenda), Psychiatry crystallised some of the myths (theories of aetiology: self-inflicted or parental blame, loss of personal responsibility) or attempted to use a medical model to restore parity of esteem with physical conditions. Thirdly, in the modern context (the post-asylum era), cultural beliefs continue to play a role in determining an individual's response to "symptoms". For the individual who becomes "ill", responses are driven by self-labelling: it may be to do nothing, initiate classic help-seeking behaviour (attendance at GP or psychiatric clinic), or it may involve secrecy, self-medication with alcohol or drugs, and delay if not rejection of help (Table 1.1).

1.6.2 To clarify stigma processes, measurement should begin at the start of interactions between perceptions of stigma and symptoms – Chapter Two begins with details of such a nonstigmatised population – people with psoriasis. Diseases of the skin affect how people appear, their social interactions, and communication.

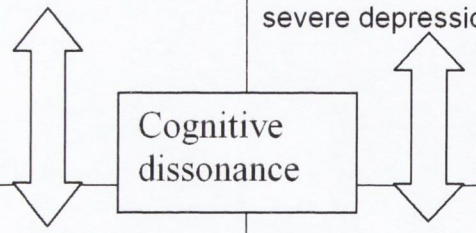
Study One examines the highly visible condition of psoriasis in comparison with people with the disabling, but less stigmatised condition of arthritis.

1.6.3 There is consensus in the psychological literature that an attitude has three components: *cognitive* (a set of beliefs), *affective* (likes and dislikes) and a *behavioural* (tendency to act in a certain way). In theory, if all three components are not sure how this worksin harmony, measuring one gives a measure of all three, most importantly behaviour. There are many mechanisms which can disrupt this harmony, for example behaviour is influenced by self-concept and group factors (Section 1.5), and contradictions can arise between beliefs or even between how we think and feel – cognitive dissonance: Table 1.2. Taking Corrigan's definition of stigma as a prejudice based on stereotypes causing discrimination, one avenue of study is to explore the stated opinions of the general public to people with mental disorders. Public attitude work uses agreement with stereotypical statements to measure of prejudice (Table 1.2). Asking the general public what they think directly is more useful than subjective evaluations of the content of television programmes or print media where prejudice is also in the eye of the beholder. Public attitudes to mental illness are a measure of stigma by proxy (Byrne, 2000). The largest study of this thesis, Study Two, is an omnibus public opinion survey of the general public in each jurisdiction on the island of Ireland. Attitudes may vary by disorder in that some components (for example, the perception of danger) may be specific to that particular disorder (for example, schizophrenia), or to a subgroup of the population. There are limitations to this approach in that contradictory attitudes (e.g. cognitive dissonance) will occur and, in several instances, we can only guess at likely behaviour of respondents. The choice is made to prioritise the cognitive components of attitudes in all three studies: Table 1.2.

1.6.4 Underlining a scientific philosophy are assumptions that psychiatrists (experts) are free from prejudicial beliefs, that experts agree and that knowledge drives

Table 1.2: Attitude components as statements in three study populations with possible attitude measures

Group / Component	Study 1. People with psoriasis	Study 2. General public	Study 2. General public	Study 3.Students & health professionals	Potential measures
Cognitive component (belief)	"My psoriasis is unsightly to others"	"People with mental illness are dangerous"	"People with mental illness are lazy"	"ECT is a safe and effective treatment of severe depression"	Questionnaires and Interviews: agreement with stereotypical statements
Affective component (feeling)	Distress, self-disgust	Feeling of threat to self / others (children) from those people	Feelings of pity for people with mental illness	ECT feels like a cruel punishment"	Physiological measurements; in-depth interviews
Behaviour	Avoidance of "normal" people	Avoidance of all people with mental illness	Beliefs about laziness compete with positive feelings: ?behaviour	ECT prescription by psychiatrists: nurses and students cannot prescribe.	Field studies; measure behaviour and discrimination
Agreement among 3	Full agreement	Full agreement	No agreement	Some agreement	



positive attitudes. In addition to testing the hypothesis that knowledge predicts better attitudes among the public (Study Two), in a third separate study, health staff and students' attitudes to Electroconvulsive Therapy (ECT) are examined. Study Three measures information and attitudes of a range of students and health professionals to ECT: this is the third group of Table 1.2. Correlations of knowledge with attitudes towards the procedure of ECT are examined. As with public attitudes, Study Three will also measure the effects of contact (seeing ECT) on knowledge and attitudes.

Section 1.7 Summary of conclusions of Chapter One

- Different disciplines have provided multiple theoretical models of stigma over 50 years. Recent work provides a basis for examining stigma-discrimination: stigma is a prejudice (attitude) based on stereotypes resulting in discrimination.
- Discrimination-only approaches are limited in scope, fail to examine unenacted prejudice, and thereby frequently underestimate the extent of stigma.
- Stereotypes are identifiable, but not quantifiable, in diverse second-hand and media representations of mental illness. Stereotype *agreement* can be measured.
- Agreement with a negative stereotype of mental illness (e.g. "people with depression are lazy" or "I think anorexics have themselves to blame") is a measure of self-stigma in an individual with depression or anorexia, but measures prejudice in others who do not have these disorders.
- Of the three components of attitudes (Table 1.2), the cognitive component is the most reliable measure, and its relationship with key determinants will be explored in three independent populations: Studies One to Three.
- Three studies (Chapter Two) will use three empirical attitudinal stigma measures to explore the mechanisms and drivers of self-stigma, public attitudes to people with mental illness, and professionals' attitudes to psychiatric treatment.

Chapter Two: The measurement of attitudes

Measuring the experiences of shame, avoidance and distress in people with psoriasis. The nature of public attitudes (prejudice), how these relate to knowledge, and the effects of familiarity (contact). The formation of treatment attitudes among health care professionals. Five hypotheses.

2.1 Attitudes to illness and self-stigma

2.1.1 One aspect of stigma, self-stigmatisation, is substantially mediated by self-reflection. Waxman et al (1992) reported that in community-dwelling older people, it was not shame which prevented them from seeking psychiatric help, but rather their own negative punitive attitudes. Goffman (1963, p94) argues that "even when an individual could keep an unapparent stigma secret, he will find that intimate relations with others, ratified in our society by intimate confessions of intimate failings, cause him either to admit his situation to the intimate, or feel guilty for not doing so". To exclude the effects of psychiatric labelling (Section 1.4) and any deleterious effects of mental health service contact, examination of psychological distress in an unlabelled but "stigmatised" population should establish useful attitude measures. Although leprosy is the archetypal stigmatising condition (Section 1.3.3), its infectivity confounds measurement of the reactions it evokes in others. To explore these issues, we will examine the non-infectious, highly visible, stigmatising skin condition of psoriasis.

2.1.2 Wessely et al (1989) examined the prevalence of psychiatric morbidity in 173 new attendees at a London dermatology clinic. 80% was interviewed with the Clinical Interview Scale (CIS), and the General Health Questionnaire (GHQ) was completed in all but 14 of their sample. The prevalence of psychiatric morbidity was 40.2% by CIS, and 42.7% by GHQ. Although their sample contained eleven separate dermatological diagnostic categories, none was uniquely associated with any psychiatric morbidity pattern. The influence of appearance ("high or low impact") determined the relationship between psychological and dermatological symptoms,

dividing their sample into three categories: Table 2.1. They describe the first group (Table 2.1) as those where skin lesions had no or low impact on individuals' distress. By contrast the second, small group had skin pathology caused by psychiatric illness. The third category was defined by the presence of high impact of skin lesions on psychological well being. The majority of these cases were described as "minor affective disorder" (Wessely et al, 1989). This third category will be considered throughout this thesis, specifically in relation to psoriasis.

Category	Impact	Description	Percent of total sample	Percent of psychiatric cases
1. Dermatological disease with coincidental psychiatric illness	Low	No interaction: psychological and physical	10%	25%
2. Psychiatric illness causing or mimicking skin conditions	N/A	Symptoms were different to 1.	9%	5%
3. Dermatological disease resulting in psychiatric distress	High	Patients report life changes after skin lesions	30%	70%

Table 2.1 Three categories of interaction between psychological and dermatological pathology, based on Wessely et al, 1989.

2.2 Psoriasis, psychological morbidity and attitudes

2.2.1 In their review of psoriasis, Gupta and Gupta (1987) concluded: "psoriasis has been associated with suicide and an increased prevalence of alcoholism. Disturbances in body image perception and the effect of psoriasis on interpersonal, social, and occupational functioning may contribute to overall morbidity". Psoriasis is common (1-2% prevalence), occurs in both genders equally, and most lesions (scalp, elbows, knees and hands) are visible in daily social interactions (Rapp et al, 1997). Zachariae et al (2002) interviewed 6,497 people with psoriasis across six countries. Two instruments, the Psoriasis Disability Index (PDI) and Psoriasis Life Stress Index

(PLSI), defined quality of life. Both will be discussed in more detail in Chapter Three. Increased preoccupations with appearance and lower quality of life were more common in women, and in younger (18-45 y.o.), single and unemployed people (Zachariae et al, 2002). There is some consensus (Lyketsos et al, 1987, Wessely et al, 1989; Folks and Kinney, 1992) that the two key psychiatric conditions which need to be measured in this group are anxiety and depression. Mood symptoms, though frequently hidden, are more conspicuous than other symptoms. Even more likely to be ignored are anxiety symptoms, both in general practice (Goldberg and Huxley, 1992) and in specific populations such as older people (Qazi et al, 2003).

2.2.2 Folks and Kinney (1992) categorise physical-psychological interactions in people with psoriasis as:

(1) the association of stress

(2) the impact of mood and anxiety disorders

(3) the influence of social support (or lack thereof), and

(4) the role of specific psychological or personality factors.

Building on the sociological constructs of Thoits and Link (Section 1.4), all four interactions will be theoretically influenced (perhaps even primarily driven) by self-reflection. If the psychological sequelae of psoriasis can be identified, it should also be possible to measure the contribution which stigma makes to their pathogenesis.

2.2.3 Nineteen studies (Table 2.2) have directly examined evidence for depression in patients with psoriasis: almost all excluded patients with joint symptoms. By contrast, RA (rheumatoid arthritis) has been the most investigated rheumatological condition with regard to psychological morbidity (Callaghan and Blalock, 1997). One condition which shares commonalities with the painful disability of RA, and the embarrasing condition of psoriasis, is psoriatic arthritis (PsA). It should therefore be possible to calculate psychological morbidity in PsA, to examine this in relation to both physical disability (function) and stigma (appearance), and compare with both

psoriasis and RA. Lyketsos et al (1987), consider psoriasis and RA as "physical conditions affected by psychological factors", though only RA and depression have been conclusively linked (Pincus et al, 1996; Callaghan and Blalock, 1997; Sharpe et al, 2001; Dickens et al, 2002). Pincus et al (1996) used the *Hospital Anxiety and Depression Scale*, HADS, (Zigmond and Snaith, 1983), and found that RA patients had twice the expected incidence of depressive symptoms compared to healthy controls, and four times the rate for anxiety. The HADS eliminated somatic questions to reduce false positives in hospital populations (Zigmond and Snaith, 1983). The relationships between psychological morbidity in RA with the effects of illness (pain, illness perception etc.) are complex, but recent work has begun to unravel these (Sharpe et al, 2001). We know that people with RA have higher rates of depression, and it would be useful to compare these with psoriasis and PsA. Prior to Study One, no study has compared measures of psychological morbidity in RA and psoriasis patients, and none has examined PsA. The theoretical assumptions here are: Psoriasis (self-stigma + disability), RA (disability only) and PsA (self-stigma + disability), measuring their attitudes to others' perceptions of them.

2.3 Alcohol excess in psoriasis: cause or effect?

2.3.1 Psoriasis-depression studies (Table 2.2) form a minority of psychosocial research into the condition. While other work examined the links with stress, more again has been related to alcohol misuse and a range of non-specific syndromes. Researchers have also attempted to identify a psoriatic personality (unproven: Baughman and Sobel, 1970; Devrimci-Ozguven et al, 1999), high / low stress responders (likely: Gupta and Gupta, 1987; unlikely: Niemeier et al, 2002), obsessionality (possible: Hardy and Cotteril, 1982), pathological worrying (possible: Gaston et al, 1987; Fortune et al, 2000), maladaptive coping strategies (possible: Hill and Kennedy, 2002; Gupta et al, 1995b; Fried et al, 1995), alexithymia (possible: Fortune et al, 2002; Picardi et al, 2003), or differences in illness perceptions

Table 2.2: *(1 of 2)* Studies of the possible relationships between psoriasis and depression:

Study	Population	Depression measure	Findings	Discussion / Comments
Fava et al, 1980	n=60 consecutive in-patients with psoriasis (20), urticaria (20) and fungal infections (20)	Kellner-Sheffield Symptom Rating Test 61-item life events scale developed by Paykel et al, 1976	Patients with urticaria had more anxiety and depression than psoriasis who exceeded those with fungal infection	Study **excluded** patients with pustular, exfoliative & guttate psoriasis. 80% psoriasis and 90% urticaria patients report at least one prior life event.
Hardy and Cotteril, 1982	12 people with dysmorphophobia, 11 with psoriasis, and 12 controls	BDI, Beck Depression Inventory Leyton Obsessional Inventory	BDI = 15.4 (9.8 SD), 9.1 (4.3 SD) and 3.9 (4.8 SD) respectively	5/12 of dysmorphophobia were severely depressed, but none of the psoriasis group.
Hughes et al, 1983	n = 196 consecutive new dermatology outpatients and 40 inpatients with common conditions	GHQ, General Health Questionnaire; Wakefield Self-assessment Depression Scale	30% of out- & 60% of in-patients scored high GHQ 15% and 33% were depressed by Wakefield	Face or hand conditions: 70% had high GHQ scores. Psoriasis predicted highest GHQ scores (4/5 cut-off).
Lyketsos et al, 1987	Nine groups incl psoriasis (n=26) and RA (n=37): during hospital admission	States of anxiety & depression scale PSE, Present State Examination	Psor: anx 7.0, depr 5.7 RA: anx 6.0, depr 6.6 PSE psor: 19% and 20% PSE RA: 11% and 54%	PSE screened other illnesses as cases except psoriasis – seen as scoring the community depression rates.
Gupta and Gupta, 1993	n = 217 patients with psoriasis: 138 inpatients + 79 less severe outpatients	Semi-structured clinical interview	9.7% passive death wish; 5.5% actively suicidal	Suicidality predicted by depression symptoms
Polenghi et al, 1994	n = 179 patients with psoriasis	Zung test for anxiety and depression	High anxiety scores (though not quantified in text of published article)	Paykel scale for stressful events: 72% in month before presentation
Fried et al, 1995	n = 64 outpatients with psoriasis (from 126 mailed questionnaires)	Subjective questions on Likert scale. Study could not claim any external validity.	High levels of depression, anxiety and anger; 48% "social embarrassment"	15% usually housebound, 33% during psoriasis flares
Harvima et al, 1996	n = 38 patients with psoriasis	BDI, Beck Depression Inventory	n = 6 (37%) depressed if cut off > 10 on BDI: a low cut off for mild depression	Concluded that depression was less clinically relevant than the stress association

Table 2.2: *(2 of 2)* Studies of the possible relationships between psoriasis and depression:

Study	Population	Depression measure	Findings	Discussion / Comments
Rapp et al, 1997	Assessment packs mailed to 517 psoriasis patients: n=297 (54.5%) response rate	BSI, Brief Symptom Inventory Suicidal ideation score	High strain (HS) group: 8% current suicidal ideation / 25% past ideas	½ HS and ¼ LS (low strain) met BSI cut-off. Distress assoc c stress not disease severity
Gupta and Gupta, 1998a	n = 217. Outpatient psoriasis patients had <30% body affected	CRSD, Carroll Rating Scale for Depression	Mood lower in psoriasis inpatients, than acne.	2.5% psoriasis outpatients & 7.2% inpatients were suicidal
Gupta and Gupta, 1998b	n = 137 patients with moderate to severe psoriasis	BSI, Brief Symptom Inventory	Stigmatised group had BSI anx of .82 (.73); depr 1.06 (.7) Control group had BSI anx of .49 (.64); depr .57 (.7). (SD)	
Devrimci-Ozguven et al, 1999	Turkish outpatients: n= 50 with psoriasis, and 50 controls.	BDI, Beck Depression Inventory	BDI = cases 16.9 (7.2) and controls 5.5 (5.3) (SD)	Regression revealed an odds ratio of 39 for psoriasis among the depressed group
Schlaroo et al, 2000	n = 69 consecutive patients with psoriasis	HADS, Hospital Anxiety and Depression Scale	Anxiety=16%; Depr= 9% 25% & 20% respct. had borderline scores	More depression (not anxiety) seen in people with more skin lesions
Kirby et al, 2001	n = 101 patients with psoriasis	HADS, Hospital Anxiety and Depression Scale	Levels not stated; PDI correlation: Anx r=0.37 & Depr r=0.49 (both $p<0.01$)	Conclusion that physical signs alone do not predict psychosocial disability
Richards et al, 2001	n = 115 outpatients with psoriasis Excluded medical illness, not PsA	HADS, Hospital Anxiety and Depression Scale	Anxiety score = 9.3; Depression score = 4.8	Depression (not anxiety) was predictive of PDI variance
Akay et al, 2002	Turkish outpatients: n= 50 with psoriasis, 30 with lichen planus (LP), with 40 controls.	BDI, Beck Depression Inventory	BDI = psoriasis 17.9 (9.5 SD), LP 16.8 (10.5), and controls 8.2 (6.7).	Severe depression (BDI > 24) 23% psoriasis for 5-10 years, 36% psoriasis for > 10 years.
Fortune et al, 2002	n = 225 consecutive attendees at one hospital	HADS, Hospital Anxiety and Depression Scale PLSI and PDI	Anxiety score = 9.9 (4.7); Depr. score = 5.2 (3.7)	Illness perception accounted for 28% of variance;
Jowlett and Ryan, 2002	Outpatients with psoriasis (n=34), acne (29) or eczema (31)	Semi-structured clinical interview	Psoriasis group: anxiety 58%; depression 24%	Qualitative study: less/no shame in late-onset psoriasis
Niemeier et al, 2002	4 groups of German outpatients with hand conditions: 26 psoriasis, 33 eczema, 14 atopic, 42 contact	Allover depression scale	No differences in scores, but 23% of psoriasis met criteria; mean was 17.9%	Divided groups into high and low stress responders

Table 2.3: *(1 of 2)* Studies of possible associations between psoriasis and alcohol misuse:

Study	Population	Alcohol measure	Association	Results / Comments
Texon, 1950	n=500 patients with alcoholism admitted to a medical hospital	Complications of alcoholism	Yes	Increased rate of psoriasis (3.1%) in their sample: greater than expected
Delaney and Lepperd, 1974	n=1,000 patients attending dermatology clinics: psoriasis and non-psoriasis	Questionnaire on "excess drinking"	No	No differences between groups, and no relation to severity of psoriasis
Grunnett, 1974	n=281 people with psoriasis: mild=150 or severe (methotrexate)= 76, + n=230 controls attending routine check-up	Units of alcohol	No	No differences between groups, and no relation to severity of psoriasis. In each group, men drank more than women.
Chaput et al, 1985	n=1,987 general hospital admissions, of which, 44 (2.2%) had psoriasis. None of the 44 patients were on methotrexate.	Alcohol consumption in grammes (g)	Yes	Psoriasis is more common is people who drink more than 50g / day, but it is not related to liver disease
Kalvi et al, 1985	n=14,667 adults in IHD study.	Frequency of alc. intoxication	No	In relation to psoriasis, 90% of any variance explained by family history.
Morse et al, 1985	n= 55 male and 44 female hospitalised psoriasis patients, 99 hospital controls	Alcoholism	Probable, but only in men	Alcoholism in 11 psoriasis, 3 controls. No relationship severity and alcohol use
Lindegard, 1986	n=159,200 inhabitants of Gothenburg; 372 (2.3%) had psoriasis	Alcoholism	Yes	Excess rates of alcoholism and urticaria, pneumonia, viral infection, hypertension
Monk and Neil, 1986	n=100 patients with chronic plaque psoriasis, divided into severe (PUVA or cytotoxic drugs) and mild (used neither).	Heavy drinker = more than 80g (8 units) alcohol / day	Yes for men No for women	Of severe psoriasis patients, 25.5% men and 4.4% women were heavy drinkers.
Braathen et al, 1989	n=149 people with psoriasis (10,576 on register): only 46% used drugs	Grams per day consumption	Yes	Smokers 48% Vs controls 36%
Zamboni et al, 1989	n=219 in-patients (136 men, 83 women) with psoriasis; 747 in-patient controls	Grams per day consumption	Yes. Also found increased fatty food intake	Men: 94.6 (+/-72.6); controls 79.1 (+/-55.4), $p<0.05$. Women: 37.1 (+/-26.3); controls 23.9 (+/-16.8), $p<0.01$
Poikolainen et al, 1990	n=144 **men** with psoriasis and 285 male "dermatology" controls, over 18 months.	100g of alcohol.	Yes (men only)	Odds ratio = 2.2 (95% CI 1.3 – 3.9). 15 refused, 15 excluded.
Naldi et al, 1992	n= 215 newly diagnosed (< 2 years) patients with psoriasis	Alcohol consumption in grammes (g)	Yes, but higher odds ratios if family history	Odds ratio 1.3 for 1-2 drinks daily Odds ratio 1.6 for >= 3 drinks daily. No association if smoking analysed too.

Table 2.3: *(2 of 2)* Studies of psoriasis and associations with alcohol misuse:

Study	Population	Alcohol measure	Association	Results / Comments
Gupta and Schork, 1993	n=48 men + n=46 women with moderate to severe psoriasis during admission	Alcohol in (g). Heavy >80g/8 units	Probable	Heavy drinking in 19% men, 7% women Male heavy drinkers: poorer outcomes
Higgins et al, 1993	n=130 people with psoriasis	Units of alcohol & dependency	Yes	19% drank > 50 units weekly; Odds ratio (alcohol → psoriasis) = 8.01
Poikolainen et al, 1994	n=55 **women** with psoriasis, 108 female unmatched dermatological controls	Alcohol in grammes (g)	No, pre-illness Yes post-illness	After onset of psoriasis, positive assoc. with alcohol, smoking, and life events
Poikolainen, 1997	n= 3,452 male & 2,235 female psoriatic inpatients. Finish death certificates.	Death rates from alcoholism	Yes	↑ Standardised mortality rate (SMR) for alcohol-related causes: 3.5 (2.8-4.4) for men, 13.6 (9.4-19.1) for women.
Poikolainen et al, 1999	Same cohort as Poikolainen, 1997	Death rates	Yes	↑ SMR all causes, especially for liver disease in men (6.98) & women (5.06)
Naldi et al, 1999	n=404 people with recent psoriasis	Units of alcohol	No* Yes in men	*when controlled for smoking: current and ex-smokers.
Akay et al, 2002	Turkish outpatients: n= 50 psoriasis, 30 with lichen planus, with 40 controls.	Alcohol yes / no.	Yes	Drinkers: 32% psoriasis, 17% lichen planus and 10% controls. Neither cigs/alcohol: 32%, 73% & 70%.
Zachariae et al, 2002	n=6,497 people with psoriasis. Questionnaire study; no control group	Not specified	Yes, weak	High consumption associated with skin disease severity and PDI & PLSI. Danish people drank more (unspecified) than others in this & previous reports.
Zhang et al, 2002	n=798 patients with psoriasis at 6 Chinese hospitals over 4 years; plus 789 controls.	Average daily consumption: 150ml of wine = 330 ml of beer = 30ml of spirits = 10g alcohol.	Yes. No alcohol dose dependent relationship	Odds ratio for drinking and psoriasis for men = 4.17 (2.8-6.2); for women = 6.6 (2.4-19.6). Study also recorded smoking habits: associations for men only; heavy smokers tended to have more severe psoriasis ($p<0.001$).
Picardi et al, 2003	n=40 people with psoriasis, with 116 matched controls (dermatology patients) *Case control study*	Drinker / non drinker	No	20% and 19% respectively were drinkers.

(probable: Fortune et al, 1997& 2002 and Schlaroo et al, 1998 & 2000). Two studies had *prospective* designs. Gaston et al (1987) reported a correlation between stress ("ongoing life events") and skin involvement, but the study was too small to conclude this association might hold for more than a minority of patients. Picardi et al (2003) failed to find an excess of life events or social support differences between psoriasis patients and controls. This is an important negative finding in doubting that life events exacerbate psoriasis: others disagree (Table 2.2). Both studies and Table 2.2's fit the paradigm of Findlay-Jones and Brown (1981) who theorise depression as related to past events (losses), while anxiety reflects uncertainty or fear of the future.

2.3.2 The majority of psychosocial studies about psoriasis have been on alcohol consumption: Table 2.3 lists 22 studies, 17 showing a positive relationship. As discussed above, Leary et al (1998) highlight a subgroup of people with psoriasis who need psychotherapeutic interventions, in particular those with fear of negative evaluations (from people around them). In their prospective study of 94 psoriasis in-patients, Gupta and Schork (1993) reported a poorer treatment response in men (but not women) who consume more than 80g alcohol daily. They did not measure alcohol consumption prior to psoriasis onset, or differentiate <u>when</u> any excess consumption occurred might clarify pathogenesis. An association with increased drinking <u>after</u> psoriasis onset (e.g. Poikolainen, 1994) supports the self-medication hypothesis (Table 1.1), and remains consistent with previous studies (Table 2.3).

2.3.3 Hypothesis 1: in people with psoriasis, self-stigma (their negative attitudes) drives their psychological morbidity and excess alcohol use.

2.4 The nature of public prejudice: what do the general public think about mental heath problems?

2.4.1 There are several reasons why psychiatrists should be aware of public attitudes to mental illnesses: these are not only the attitudes held by people before they become *patients*, but they are also indicative of the environment in which they treat

their patients (Rabkin, 1974). Knowledge of this mental health environment remains essential for clinicians providing modern community treatment at all stages from early intervention to rehabilitation. She also concluded that: "despite longstanding awareness of the discrepancies between what people say and what they do, the link between attitude and behaviour has been deemed sufficiently meaningful to warrant extensive research regarding public attitudes towards mental illness" (Rabkin, 1974). Negative attitudes are directly associated with both intended (Beck *et al.*, 2003) and actual behaviour (Corrigan *et al.*, 2004). A meta-analysis of the empirical literature which confirms a direct relationship between stated attitudes and behaviour (Kraus, 1995). It is worth noting that attitudinal work (Rabkin, 1972 & 1974) was drawn upon by both Scheff (1966 & 1975) and Thoits (1985 & 1991) in evolving diverging sociological constructs: Section 1.4. Trute et al (1989) argue that public opinion about mental illness has acquired even more importance with the introduction of community care programmes, specifically the relocation of patients in (potentially) hostile neighbourhoods. Leff (2001) acknowledges poor public perceptions of "care in the community", now itself a slang term for people with mental illness. He criticised anti-stigma campaigns: "none … focuses on educating the public and the media about the reality of community care".

2.4.2 Link and Cullen (1983) have provided a theoretical critique of public attitude work. They identified two contrasting positions from the literature: (a) that there is minimal stigma (because the public express acceptance in general) or (b) that stigma (measured as prejudicial attitudes in public opinion surveys) is a major determinant of outcome. They found empirical support for the latter position. Although the public has "learned" that it is socially unacceptable to reject people with mental illness, it is possible to identify "private, less socially desirable sentiments" when appropriate comparisons are made. Responses to people with mental illness comprise:

(1) The Ideological Level: socially correct, *ideal*, determined by the "experts"

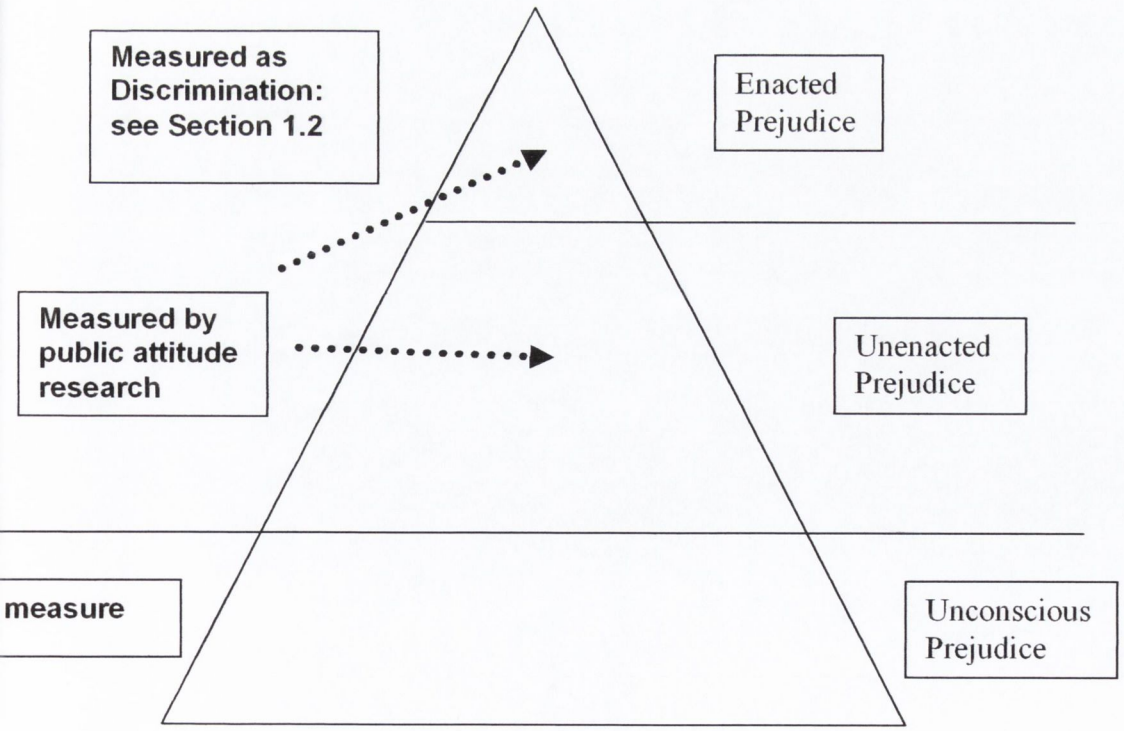
(2) The Level at which Attitude is expressed: a dipositional state that determines behaviour. Influenced by the Ideological, but different from the ideal belief

(3) The Level at which Attitude is acted on: closer to intrinsic beliefs but rarely surface when individuals fill out direct questionnaires, and

(4) The Deep Level: deeply embedded cultural beliefs. Seen in unconscious language and images of mental illness (see Section 1.3).

Using a single-phase random sample of 300 US community residents, they showed that attitudes to mental patients became progressively worse with each category – from the first to the fourth. They measured what respondents indicated "most people" thought about illness, and this was compared to the ideal belief (first category) and what they believed (second category). Labelling (being told the person is mentally ill) increased the differences between lower categories, revealing more marked "negative" attitudes across all four. They found subtle negative beliefs about people who are ill, even in those who on the milder end of the spectrum of mental illness, in this study, anxiety-neurosis (Link and Cullen, 1983). Figure 2.1 posits a theoretical model of prejudice:

Figure 2.1 Three Levels of Prejudice, based on Link and Cullen, 1983.



2.4.3 All societies provide cognitive schemata for their citizens to categorise new and familiar people they encounter. These associations are learned, coached by family, sub-cultural and cultural forces (e.g. media representations). Key to these processes are identifiable markings or recognisable stereotypes in the world about us. For prejudice to exist, there must be automatic rejection based on agreement with the stereotype. Biernat and Dovidio (2000) summarise stereotypes' research:

- Stereotypes operate as cognitive structures that influence how information is encoded, stored, and retrieved
- In order to feel negatively towards a group, we must be able to attribute certain constant, undesirable characteristics to them (see Section 1.1.1)
- Negative stereotypes perform a useful function for prejudiced people by allowing them to rationalise their hostility towards members of the out-group
- Prejudice is activated by the presence (real or imagined) of the out-group
- In field studies where confederates do not have mental illness and have been told nothing about how to behave, most observers (so informed) believe that *they* (the confederates) conform to the internalised stereotype

There is however a resonance within some stereotypes that reality is reflected in part. For Allport (1954), stereotypes function as rational categories that "grow up from a kernel of truth". A working example here is of one of the four mental illness stereotypes (Section 1.3.5), the psychokiller. Nunnally (1961) observed that "some of the 'bad' attitudes that people have toward the mentally ill are partially supported by the facts – for example the mentally ill sometimes *are* (his italics) unpredictable and dangerous".

2.4.4 This thesis is underpinned by the identification of stereotypes, in the media (Section 1.3.5), throughout Goffman's original work (Section 1.4.1), mediated by social psychological processes (Section 1.5.2) and expressed as attitudes (Corrigan, 2003). Rutland (1999) has examined how stereotypes drive the pathogenesis of prejudice. Taken together, the dimensions that comprise mental illness stereotypes might be related to perceptions of violence, aetiology, personal responsibility, treatment effects, outcome, and social distance in relation to mental disorders. Each

disorder (of the six disorders studied in Study Two) will be considered in turn. Due to differences in prevalence rates, the disorders will show variations in awareness, contact and knowledge, but beyond these, they attract different stereotypes.

2.4.4.1 Evers (in Crisp, 2004) charted public awareness of **Alzheimer's dementia**: this rose from 57% in 1989 to 91% in 1998, perhaps following the public disclosure of the condition in former US President Ronald Reagan. While one would expect low blame scores for people with this condition, there may be age-related factors that influence this. Bytheway (1995) draws on "old person" stereotypes as the means of inequality of esteem. Some older psychotherapy textbooks continue to list old age as a contraindication to treatment: drawing on Freud's eligibility criteria ("not too old, not too ill"), Crown (1979) endorsed the YAVIS guide, defining the acceptable patient as Young, Attractive, Verbal, Intelligent and Successful. In a survey of US physicians about late life depression, most saw low mood as "understandable", but older physicians saw stigma as a barrier to diagnosis (Gallo et al, 1999). Greenwood (2000) has examined substance misuse in older people, identifying a series of prejudices in health professionals, that prevents both recognition and treatment.

2.4.4.2 McKeon and Carrick (1991) reported that over two thirds of an Irish sample did not believe **depression** was an illness. By contrast, one of the claims of the UK Defeat Depression Campaign was a significant increase in the percentage of the UK public who agreed that depression is a medical condition, from 73% to 81%, although only 5% of respondents had heard of their campaign (Paykel et al, 1998). Disease or not, depression is probably the most recognised of the six disorders. Despite this, there are perceptions that it is self-inflicted, a sign of weakness, and evokes pity – the deserving mad (Byrne, 1997). Although the UK public has consistently endorsed "counselling" for people with depression - over 90% in three MORI polls (Paykel et al, 1998) - Crisp et al (2000) reported 49% agreement with the statement that people with severe depression should "pull themselves together".

2.4.4.3 Fieldwork to reduce stigma (Penn et al, 1994 & 1999; Pinfold et al, 2003) has prioritised **schizophrenia**. A UK study showed 53% still believed that it meant *split personality* (Department of Health, 2003). In his first person account, Anthony Scott invoked the danger stereotype: "strangers who treated me with the sympathy I needed were rare. I was glad when they responded to me with nothing more than indifference... I am grateful, in the light of popular misconceptions about schizophrenia, that I never committed a crime" (Scott, 2002). In the UK, studies of the general population (Crisp et al, 2000 & 2005), and of medical students (Mukheriee et al, 2002), have shown that highest antipathy is towards people with schizophrenia and addictions. A minority of GPs are reluctant to have people with schizophrenia on their lists (Lawrie et al, 1998).

2.4.4.4 1 in 6 people meets the diagnostic criteria for **anxiety disorders** over one year, though two thirds receive no treatment (Davies, 2000). Sobriquets such as "the worried well", *neurotics* and *hysterics* hint at stereotypes of character weakness and indulgence. As an illness, it fails to command respect or therapeutic concern – perhaps tainted with adverse attitudes to benzodiazepines, drugs once advocated as its "cure" (Taylor, 1989). Although anxiety is the primary symptom in 10% of primary care consultations, many clinicians believe that identifying this as "psychiatric", adds to stigmatisation with connotations of madness, and employers' perceptions of these patients as a liability (Davies, 2000). One Irish GP described this group as "people pouring out their problems in the surgery and dumping them on my doorstep. It would be really unbearable if I was actually listening to them" (Waters, 1999).

2.4.4.5 Despite the fact that over 90% of the UK population drink **alcohol**, when dependence arises, there are strong public beliefs about self-infliction, loss of control, unpredictability, violence and resistance to being helped (Ritson, 1999). Because of the powerful stereotype of the alcoholic as "down and out", doctors frequently miss alcohol problems in (the more common setting of) employment (Ritson, 1999). Dean and Rud (1984) interviewed residents from a Midwestern US town to assess their first impression images of the term "**drug addict**." The results indicated that the

overwhelming image was of a disoriented, unhealthy, thin, low- class, male "hippie" with behavioural and skin problems. Although addiction and eating disorders carry the highest mortality of mental disorders (Harris and Barraclough, 1998), both have been conferred with the least amount of public empathy, and this has been linked to attributions of responsibility (Corrigan, 2000). Most challenging is the coincidence of substance misuse and schizophrenia, "dual diagnosis", where basic clinical services and research models are lacking (Weaver et al, 1999; 2003). Cape (2003) identifies three addict stereotypes in film: the tragic hero, the demonised and comic user.

2.4.4.6 Attitudes to **eating disorders** have been studied least of all. Gowers and Shore (1999) found public beliefs about self-infliction and poor communication and secrecy, but assumed the public's views about outcome were less favourable than professionals'. The most negative attitudes recorded are professionals' (Fleming and Szmukler, 1992). Shelley (in Crisp, 2004) describes her experience of anorexia, including being pointed at in the street, and being asked "what sort of impression (she) felt (she) was giving to impressionable young girls". Common eating disorder stereotypes have been identified as female, young, middle class and susceptible to outside influences, especially the media (O'Grady and El-Sobky, 1987).

2.4.4.7 Hypothesis 2: the public differentiates six mental disorders: each has a unique profile based on awareness, knowledge and key attitudes.

2.5 Information versus Attitude

2.5.1 In researching the general public's views about mental health, Nunnally (1961) drew a clear distinction: on the one hand, there is *information* ("uncrystallised and expressed tentatively without much assurance") and on the other, *attitudes* (personal beliefs). Rabkin (1974) sums up the conclusions of pre-1970s work: "bad attitudes were not held because of existing (true) information or misinformation about mental illness by the public but, rather because of lack of information". Trute and Lowen (1978) confirmed the distinction as to whether the public is "uninformed" (they lack information) or are

"misinformed" (they are prejudiced). In public opinion research about mental illness, the relationships between awareness, knowledge and attitudes are complex: Figure 2.2. The first four pathways underpin a public health approach to stigma where education achieves transition to category 4. Campaigns (for example *Defeat Depression* and *Changing Minds* of the Royal College of Psychiatrists) have applied a broad educational approach to convert members of this fourth category. In medical terms, knowledge is the vaccine which treats the "illness" of negative attitudes.

1.	No Awareness: → ***uninformed*** → negative attitude (prejudice)
2.	Awareness: no knowledge → ***uninformed*** → negative attitude (prejudice)
3.	Awareness: poor knowledge → ***misinformed*** → negative attitude (prejudice)
4.	Awareness: good knowledge → ***informed*** → positive attitude (no prejudice)
5	Low awareness/knowledge → **misinformed** / ***uninformed*** → positive attitude
6	Awareness: good knowledge → ***informed*** → negative attitude (prejudice)

Figure 2.2 Awareness, knowledge and attitudes

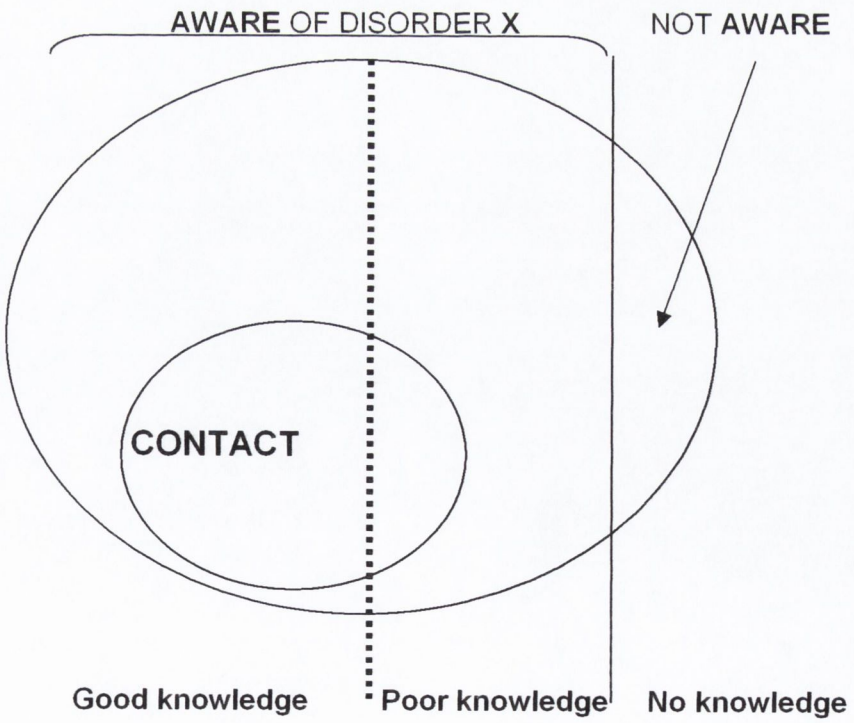


Figure 2.3 Relationships of three parameters to each other for six disorders

We know from the social psychological literature (Section 1.4) and from cognitive dissonance theory (Section 1.6.3) that it is possible for knowledgeable people to hold prejudicial views: category 6. Perversely, there may be groups who are unaware of a mental disorder, but have positive attitudes when it arises: category 5. Interactions between awareness and knowledge are set out as Figure 2.3. In Study Two, parameters will be established for each of six mental disorders (X): *awareness* of X, *personal contact* with someone with X and perceived *knowledge* about X. Only those who are aware can have contact with or knowledge of the disorder: (Figure 2.3).

2.5.2 Recognition of mental disorders is high, especially in the latter half of the last century: Flaskerud and Kviz (1983) reported recognition among US rural residents of depression, schizophrenia, alcohol and drug misuse as 98% or more. A public health model (Figure 2.2) would expect that low awareness parallels negative attitudes. Where knowledge has been measured, it is lower in men, older people, people on lower incomes and those with relatively less education (Angermeyer and Dietrish, 2006). There is anecdotal evidence that older Irish people are more rejecting of many stigmatised groups: lone parents, same sex couples, people with tuberculosis etc (cf *Valley of the Squinting Windows* by Brindsley McNamara), and McKeon and Carrick (1991) found higher levels of negative attitudes to depression among older Irish people. Marriage might be a proxy measure of contact with someone who has the disorder, and this will be examined as a possible confounder. 2.5.3 The judicious use of Electroconvulsive Therapy (ECT) is cautiously advocated in the UK (Royal College of Psychiatrists, 1995), the US (American Psychiatric Association, 1999) and the antipodes (Royal Australian and New Zealand College of Psychiatrists, 1981). However there is wide variation in ECT prescription: Olfson et al (1998) report rates of ECT use from 3.8% (1.3-6.3, 95% CI) to 15.3% (9.0-21.6, 95% CI) in US Mountain and West North Central regions respectively. They excluded Southern US states where ECT use has always been low, and reported that, as expected, older people were more likely to receive ECT, but the wealth of patients (white, living in more

affluent areas and with private health insurance) was *directly* related to receiving treatment (Olfson et al, 1998). Both findings, that there is wide variation in ECT use and that it is unlikely to be prescribed to poorer or black Americans, replicated the work of Thompson et al (1994). In a small Texan study, Finch et al (1999) report that 93.8% of psychiatrists agreed that ECT should be available for prescription, but this group referred only 4 patients in the previous 6 months, a total of 16 over two years. Hermann et al (1998) reported that less than 8% of US psychiatrists provide ECT for their patients, and found strong associations between their training (graduation before 1980) and subsequent ECT prescription. Glen and Scott (1999) reported a 40% decrease in ECT prescription over six years in Edinburgh and a New Zealand study identified a minority (5%) of consultants strongly opposed to ECT (Strachan, 2001). There are regional variations in Ireland: in-patients in the South East are six times more likely to receive ECT than those in the South, and those in the West five times more than the Midlands (Gueret, 2003). In an Irish survey, Latey and Fahy (1988) concluded that psychiatrists' attitudes and patient turnover rates could explain some of the inter-hospital variations. In the first study of its kind, Kalayam and Steinhart (1981) administered the same questionnaire to psychiatrists, psychologists, psychiatric nurses and social workers, and patients who had received ECT. They reported minor differences between groups, and concluded that psychologists' answers correspond most closely to patients' (Kalayam and Steinhart, 1981). Of 18 ECT attitude studies, this study is one of only three which applied the same instrument across multiple disciplines: (Table 2.5). Benbow (1990) reported the effects of routine psychiatric training on the attitudes to ECT of medical students: knowledge (information) and attitudes improved following a clerkship that included direct contact with ECT. Szuba et al (1992) replicated these findings in US medical students and psychiatric residents. Although causality cannot be implied, any relationships between knowledge deficits and negative attitudes would support targetted educational interventions here. All 18 studies of Table 2.5 advocate better

Table 2.4 Quantitative studies of professionals' and students/ attitudes towards ECT

Authors	Group(s) studied	Knowledge measured	Intervention	Main findings
Farrant et al, 1979	108 Ugandian med students	No	Yes	Lecture did not change attitudes to unmodified ECT
Kalayam and Steinhart, 81	n=587 : see text, 5 groups	No	No	Psychologists' attitudes correspond closest to general public's
Janicak et al, 1985	n=200 US professionals	Yes	No	Increased knowledge associated with positive attitudes
Poster et al, 1985	n=35 US nurs students	Yes	Yes	Video improved knowledge and attitudes
Benbow, 1990	UK medical students: n=60	Yes	Yes (one group saw video)	Contact improves negative attitudes: *After clerkship:* better more quickly than meds: 92%; last resort: 7%
Jaffe et al, 1990	n=29 US trainees	Yes. 10-questions	No	52% strongly in favour and 21% comfortable with ECT
Szuba et al, 1992	n=35 US trainees & med students	Yes	Yes (before & after)	For trainees, knowledge correlated with prescription: $r=0.75$, $p<0.001$
Haddad & Benbow, 93	n=261 UK Anaesthetists	Yes	No	As good as / better than meds: 62%
Andrade & Rao, 1996	n=165 Indian medical students	Yes	No	ECT causes pain: 75.5%; brain damage: 19%; only as a last resort: 45.4%; should be banned: 12.9%
Gass, 1998	UK mental health nurses: n=167	Not stated	No	25% -37% either unsure or incorrect about facts about memory. More qualified nurses had more knowledge
Clothier et al, 2001	US medical students: n=90	Self-rated knowledge	No	Causes pain: 53%; Brain damage: 24% Last resort: 23%
Lutchman et al, 2001	n=268 UK CMHT: four groups	Instrument = QuAKE	No	Should be banned: 12% A cruel treatment: 20% Discipline predicts attitude
Walter et al, 2002	n=94 Australian & UK med studs	No	Yes	Causes personality change: 36% Causes burns: 20%. Viewing negative images reduced ECT support
Chakrabarty et al, 2003	Indian doctors incl psych n=100	Yes	No	Knowledge did not predict attitudes. ECT causes pain: 63%; brain damage 58%;
Culas et al, 2003	n=75 UK CMHT	No	No	28% could not be certain about ECT safety
Gazdag et al, 2005	n=55 Hungary med students	Yes	No	Dangerous 50%; causes brain damage 32%; used as punishment 2.4%
Papakosta at al, 2005	n=161 Greek med students	Yes	Yes	Dangerous 5.6%; brain damage 2.5%. Lecture improved pos attitudes further
Warnell et al, 2005	n=122 US med students	Yes	Yes (video or lecture)	Clerkship improved knowledge and attitudes; both interventions improved knowledge only – with no differences between interventions

training as a way of improving ECT attitudes, and thereby its prescription.

2.5.4 Most early opinion research assumed that the more people knew, the less stigmatising their attitudes became (Rabkin, 1972 & 1974) but there is evidence (Cumming and Cumming, 1957A; Altrocci and Eisdorfer, 1961), that imparting knowledge to the public *on its own* does not consistently alter attitudes. Jorm et al (1997a) go beyond the arguments of Section 2.4.1 in prioritising knowledge as achieving better attitudes to mental illness. The lifetime prevalence of common mental disorders is high, such that the majority of the population will experience these either themselves or in a close personal friend or family member. The term, *mental health literacy* (MHL), is proposed as "the ability to recognise specific (mental) disorders, knowledge of how to seek mental health information, knowledge of risk factors and causes, knowledge of self-treatments of professional help available, and attitudes that promote recognition and appropriate (sic) help-seeking" (Jorm et al, 1997b; 2000). In practice, high MHL in a population means that they share the same belief systems (about aetiology, course, best treatment and prognosis) as psychiatrists. However, to state the obvious, psychiatrists, who have the highest MHL, can also have stigmatising attitudes (Mukherjee et al, 2002). MHL derives from the Health Belief Model: psychiatrists have knowledge, the public have folk beliefs and if only *they* knew what we do, everything (compliance, service use, stigma) would improve (Petrie and Weinman, 1997). Lay beliefs were wrong or "at best watered down versions of proper professional medical knowledge i.e. no more than old wives tales" (Stainton Rogers, 1991).

2.8.2 There are three principal reasons why health professionals' attitudes to psychiatric treatments are of interest in stigma measurement. Firstly, many previous anti-stigma campaigns were based on a medical model of stigma as a sort of illness, for which knowledge is the cure. To test this, it would be useful to identify a context where, even in the presence of knowledge, acquired through professional training, negative attitudes prevailed: category 6 of Figure 2.2. This would also counter the

argument that the public merely needs to be informed about the efficacy of psychiatric treatment for stigma to recede. Secondly, although it is possible to administer the same mental illness attitude scales to lay people and professionals (Mukherjee et al, 2002: Kingdon et al, 2004), the latter group are more astute with more idealised responses. There is a growing literature on patients' attitudes to psychiatric treatment, but there are many potential confounders: intercurrent illness, negative experience of staff or hospitalisation, sample heterogeneity, external validity and (unknown) prejudicial factors: Table 1.1. Studying treatment attitudes among (relatively homogeneous) mental health professionals is also more straightforward than the examination of public attitudes to mental illness. Thirdly, if attitudinal differences between health professionals can be identified, it might be possible to examine whether remediable properties inherent in education (nursing or medical, including specialist medical training) could change treatment attitudes. Of all psychiatric treatments, ECT has been the most rigorously tested, through large placebo-controlled trials (Weiner, 1994; Scott, 1998; Geddes et al, 2003). Among the general public, ECT remains controversial (Freeman et al, 1986; Durham, 1989). Surveys of the public's attitudes to psychiatric treatments have consistently shown that ECT is seen as the least favourable option (Jorm et al, 1997). Common myths pervade: that it causes brain damage (Durham, 1989; Devanand et al, 1994), that it is a painful procedure, that it is used as a punishment or an agent of social control (Fox, 1993) and given to people against their wishes (Salzman, 1977). Mental health professionals often recount anecdotes of having to unlearn their own beliefs (acquired as members of the general public) about how best to treat mental illness during the course of their training. Given that all students and professionals are members of the general public, it would be useful to examine their knowledge of, and attitudes to, ECT. Analogous to the placebo effect of medications may be the negative effect of staff attitudes on treatment outcomes. Stern et al (1999) examined the attitudes of mental health professionals, and found differences between social

workers, psychologists and psychiatrists in their preferred treatments for depression (psychotherapy and medication). The parallel here with drivers of public attitudes may be that despite empirical evidence that ECT is effective (Information), staff may have emotional views or other antipathies (Attitude) to this treatment. The relationships between knowledge and contact can also be examined in the formation of attitudes, whether they are positive (more likely to consider ECT prescription) or negative (unlikely to consider ECT). There are however no longitudinal studies which returned to the intervention group years (or even months) after the educational event. If nursing students are shown to have broadly favourable attitudes to ECT, but qualified nurses report negative ones, this finding would support the paradigm that educational gains may be short term, and other interventions need to be considered.

Hypothesis 3: Levels of knowledge about psychiatric disorders and their treatment promote more positive attitudes

2.6 Drivers of negative attitudes: beliefs about the illness or the person

2.6.1 Many early studies about the aetiology of mental illness uncovered rejecting attitudes based on blame, drawn on interviews with people from Judeo-Christian traditions. Recalling the "sin of madness", Ramsey and Seipp (1948) reported high proportions of New Jersey people believing insanity to be "God's punishment for some sin or wrongdoing". This belief was significantly less common in respondents with higher educational attainment and in better paid occupations. 15% of Edinburgh residents believed masturbation caused mental illness (Maclean, 1969). Sellick and Goodear (1985) reported younger people acknowledged a greater influence of interpersonal experiences on mental health, finding lower blame scores. Angermeyer and Matschinger (1994) have studied lay beliefs about schizophrenia in Germany, then divided into East and West Germany. About half of respondents listed constitutional weakness and lack of will as possible causes of schizophrenia, and out of a possible 17 factors, only these two (along with work difficulties) were associated with significant difference between jurisdictions. West Germans were more likely to

endorse the biological view and East Germans had a blaming explanation. Only a tiny minority (between 2 and 5%) cited the Will of God, witchcraft / possession or signs of the zodiac as causal factors. A 1994 Canadian study elicited 24% agreement with the statement that people (with mental illness) are weak or lazy, with 20% endorsing the view that they should "shape up" (Arboleda-Florez, 2003).

2.6.2 Historically, there has been widespread *professional* pessimism about the public's attitudes to psychiatric treatments: "many clinicians are familiar with the fact that relatives often do not desire or expect a cure to be effected by a mental hospital" (Johannssen, 1969). Forty years ago, the public considered psychiatric treatment as more frightening than surgical intervention (Nunnally, 1961). Some stigma commentators (Clausen, 1981; Lamb, 1999; McGuffin, 1999) have opined that what is needed most to challenge stigma is the widespread dissemination of the realities of psychiatric treatment successes. The efficacy argument runs thus: stigma will reduce (and disappear) as the public learn that mental illnesses are treatable (Inouye, 1983; Satcher, 2000). Gove (1975) used the *treatment cures stigma* argument to counter the "simplicity" of Scheff's Labelling Theory (Section 1.4.4). This argument is based on several assumptions, principally that the public is mostly negative about treatment outcomes. Published studies have contradicted this assumption. Lemkau and Crocetti (1962) found the public anticipated *total cure* in case vignettes with paranoid schizophrenia (79%), simple schizophrenia (72%) and alcoholism (56%). Crocetti et al (1971) reported 89% agreement with the statement that "most people who are mentally ill can be cured with proper treatment". Angermeyer and Matschinger (1994) have reported highly informed lay beliefs about outcome in schizophrenia: they agreed it had a poor natural history, but with optimum treatment, one fifth believed in cure and about half felt symptoms would completely disappear for at least certain periods of time. McKeon and Carrick (1991) reported a Republic of Ireland (RoI) study on public attitudes to depression treatment: 70% said that it could be successfully treated – optimism unlikely to be matched by Irish health professionals.

2.6.3 Drawing on the information-attitude distinction of Section 2.5.1, Nunnally (1961) argued that information would be sought if it allays the public's immediate fears (of becoming mentally ill) and offers facts about causes and early warning signs. Maclean (1969) reported that 70% of her Scottish general public sample "expressed horror" at the idea of developing a mental illness. Current fears about mental illness may have changed in that fear now relates not to fear of becoming ill but to violence by people who are mentally ill: Section 1.3. For Spiro et al (1974), "the operative definition of mental illness for the public is the stereotype of violent, assaultive behaviour". Hollingshead and Redlich (1958) confirmed high levels of public fear and hostility. An interesting aspect of class influences on attitude was the finding that lower social class was associated with more fear, but higher status was linked to greater feelings of shame and guilt. Wolff et al (1995a & b) identified middle class parents of young children as having significantly more negative attitudes about violence by people with mental illness. The *a priori* hypothesis of Study Two is that danger is the strongest driver of negative attitudes. Perceptions of violence among the public reduces help-seeking: the majority of an older group sampled saw mental health services as provided to incarcerate violent people. This belief was more likely to be held by Black African-Caribean elders (Marwaha and Livingston, 2002).

2.6.5 Hypothesis 4: fear of the person has replaced negative judgements about aetiology and treatment outcomes as the driver of negative attitudes.

2.7 Contact

2.7.1 As a potential confounder, contact needs to be eliminated from analyses of the demographic determinants of knowledge and attitude. Contact will ensure 100% awareness (Figure 2.3), but we cannot assume it improves knowledge, and, *quite a separate matter*, negative attitudes. Put simply, if beating stigma is all about contact, anti-stigma initiatives should focus merely on increasing contact, rather than attempting to directly influence knowledge or negative attitudes in the general public. Whether Allport's contact hypothesis (the act of meeting a member of the stigmatised

group reduces prejudice) applies to mental illness stigma has been answered inconsistently in the literature. Many studies *disagree* that contact with someone who has been ill always improves attitudes: Maclean, 1969; Bord, 1971; Graves, 1971; Sellick and Goodyear, 1895; Caetano, 1987; Weller and Grund, 1988; Trute et al, 1989; Arkar and Eker, 1992; Murphy et al, 1993; Levey and Howells 1995; Rossler and Salize, 1995; Callaghan et al, 1997; Fan, 1999; and Al-Adawi et al, 2002. An early interventional study, Altrocci and Eisdorfer (1961), did not achieve more positive attitudes among student nurses following a lecture series, but did achieve these when students had direct professional contact with patients as part of their academic course. Two Irish studies found no association between contact and attitudes (Barry and Greene, 1992; Murphy et al, 1993), but no Irish studies to date have examined the demographic associations with contact. In the light of the negative evidence above, it is better to examine contemporary research. Rabkin (1981) judged that community reintegration of psychiatric patients had become more complex, not least "the acutely ill and chronically disabled patients seen on the street with increasing frequency today". Here, contact would be expected to increase social distance and perceived unpredictability. Corrigan et al (2000 and 2001b) have stated that contact between a potential stigmatiser and someone with mental illness should be based on equality, and in a positive setting. This might explain why contact fails to improve attitudes in student and health professionals (Callaghan et al, 1999; Roth et al, 2000; Llerena et al, 2002). Modern general public studies (see Angermeyer and Dietrich, 2006 for a review) found universally positive effects of contact on attitudes.

2.7.2 Medical and nursing students who train in psychiatry are all assigned to observe the preparation and administration of ECT to patients on their firms. It would be expected that their questions will be answered, their doubts assuaged.Three questions arise from four intervention studies (Table 2.5):

(1) do benefits of improved attiudes endure after clerkship and throughout their professional careers?

(2) can findings be generalised? and

(3) is it the clerkship including lectures or the actual direct contact with ECT that effects the changes?

Positive attitudes were associated with more ECT contact and better knowledge levels about ECT, and the latter appeared linked to years' experience (Table 2.5). Study Three defines contact for students and qualified respondents (Section 3.3.4.3) and attempts to separate the effects of lectures from actual face to face contact. The second question above is also addressed in Study Three by studying populations by location (Dublin and Cork) and by profession (nursing and medical students / graduates). Studying two locations also draws on findings of Gass (1988) that location determined ECT attitudes.

2.7.3 Hypothesis 5: Contact with a person or a treatment predicts better knowledge and more positive attitudes.

Chapter Three: Methods

Section 3.1 Study One

3.1.1 Study One measures markers of physical disability, alcohol use and psychological morbidity in three related populations: skin only, joint only and skin plus joint disease. Study One measures mood and anxiety symptoms (Section 2.2.2) and examines their association with stigma in people with psoriasis and PsA. This latter hypothesis, of an association between outward appearance (stigma) and psychological morbidity, has two potential confounders: alcohol use (Section 2.3) and the direct effects of chronic physical illness. Study One therefore includes a control group of patients with RA, against which psoriasis patients are examined.

3.1.2 Sample

All patients were recruited from consecutive attendances at the St. Vincent's University Hospital, (Dublin 4, Ireland) Rheumatology outpatient clinic and from Hume Street Hospital (Dublin 2) dermatology outpatient clinic and wards. A third source of patients were inpatients at the St. Joseph's Hospice, Harold's Cross, Dublin 6: these were outpatients of St. Vincent's Hospital, referred for hospital admission to St. Joseph's Hospice for intensive inpatient treatment. RA was diagnosed according to the ACR criteria (Arnett et al, 1998). PsA was defined in all cases as a seronegative inflammatory arthritis in the presence of definite plaque psoriasis and in the absence of a positive rheumatoid factor (Veale and FitzGerald, 2002). The diagnosis of psoriasis was confirmed by a consultant dermatologist (SR), working at Hume Street Hospital.

3.1.3 Design

This was a cross-sectional case-control study conducted at three different sites. In total, 253 patients were asked to participate in the study and 8 refused, yielding 245, a participation rate of 96.8%. One patient with PsA, 2 patients with RA and 5 patients with psoriasis declined to participate, mostly citing a lack of time as the reason for

non-participation. A single, semi-structured interview was performed and recorded by one observer (PB, PdB, or DK), who had access to their case notes. All patients were assured of the confidential nature of the interview. This process recorded demographic data, disease and medication history, and five instruments listed below. All patients signed a consent form, having had the opportunity to read a one page patient information sheet and have their questions answered about the study. The Ethics Committee of St Vincent's University Hospital, Dublin approved the study.

3.1.4 Instruments

1. Hospital Anxiety and Depression Scale, HADS (Zigmond and Snaith, 1983). Although previous studies which measured mood symptoms in patients with psoriasis used different instrument to measure mood symptoms, the most common was the HADS, used in four studies (Table 2.2). Wessley and Lewis compared the HADS with the General Health Questionnaire (GHQ) in a population of dermatology patients and reported no significant differences in sensitivity and specificity between the two instruments (Wessley and Lewis, 1990). The basic psychometirc properties of the HADS are good in terms of factor structure, intercorrelation and internal consistency (Mykletun et al, 2001). Moorey et al (1991) reported internal reliability, r, for each factor of +0.90. Many studies of psychological morbidity in RA (Section 2.2) used the HADS, and, relevant to Study One, it has also been validated in an outpatient alcohol treatment clinic (Vassilas et al, 1995).

2. Psoriasis Disability Index, PDI (Findlay and Kelly, 1987) measures functional impairment caused by psoriasis with questions on a 7-point Likert scale. Questions relate to experiences over the past four weeks: "how much has psoriasis interfered with you carrying out work around the house or garden? how much more do you have to change or wash your clothes? has your psoriasis been much of a problem at the hairdressers?".

3. Psoriasis Life Stress Inventory, PLSI (Gupta and Gupta,1995), designed to explore psychosocial stressors ("chronic, low-grade stress or daily hassles") in people with psoriasis. Four self-stigma questions of the PLSI are listed as Box 3.1

Box 3.1: Modified PLSI questions

- feeling self-conscious among strangers;
- not going to a public place (swimming pool, health club, restaurant etc.) when you would have liked to;
- avoided sun bathing if others are present;
- worn uncomfortable or unattractive clothes to cover certain areas of your body.

For each question, there were four possible answers about the stress caused:

None (0) A slight degree (0) A moderate degree (1) A great deal (2)

The majority of recent psychosocial psoriasis studies (Table 2.2) have used the PLSI. This selective use of four PLSI questions has not been used by other researchers, but the questions were believed by the principal researchers (PB and DK) to have good face validity for key stigma responses, feeling self-conscious and avoidance: Section 1.4.

4. Health Assessment Questionnaire, HAQ (Arnett et al, 1998). This measures function in patients with rheumatological disease. Eight parameters (dressing, arising, eating, walking, hygiene, reach, grip and activities) are marked on a 4-point Likert scale. Each score (range 0 to 3) is divided by eight and added to the other 7 parameters. A visual analogue scale (15 cm long) for subjective experience of pain is included at the end of the HAQ.

5. Alcohol consumption in all subjects was quantified by structured interview. Firstly subjects were asked to quantify in a drink diary the number of units of alcohol consumed "in the week just finished" (Monday through Sunday). They did this for

each day for: beer (one pint equals 2 units), cider (one pint equals 2 units), wine (one glass equals 1 unit) and spirits (one measure equals 2 units in Ireland). They then described a typical week's consumption, with the exclusion of Christmas or holiday seasons. In all subjects, data on a typical week's drinking was analysed. For subjects with psoriasis, two additional questions were asked: (1) "try to remember the time before you got psoriasis. Since then have you been drinking (a) less alcohol (b) just the same or (c) more alcohol and (2) How does drinking alcohol affect your psoriasis: (a) makes it better (b) makes it worse or (c) no effect" – *choose one* for each.

3.1.5 Subjects

Consecutive patients atttending with psoriasis (n=92), PsA (n=69), and RA (n=84) participated in the study. The diagnosis of PsA can be made in the absence of psoriasis if the pattern of arthritis is atypical and there is non-fungal nail dystrophy or a postitve family history of PsA (Veale and FitzGerald, 2002). Because we wished to examine the psychosocial effects of psoriatic skin lesions, we excluded PsA patients who had no skin involvement from the study. There were no other exclusion criteria.

3.1.6 Interviewers

Three interviewers (PB, PdB or DK) carried out the study. PdB (who carried out the majority of interviews) was a medical student attached to the Department of Rheumatology, St. Vincent's Hospital for the purpose of this study. DK was a lecturer in Rheumatology and PB was senior registrar in Psychiatry, both at St. Vincent's Hospital. A score sheet for each instrument was piloted and agreed prior to the study.

3.1.7 Procedure

The diagnosis (psoriasis, PsA or RA) was confirmed from the case notes prior to interviewing the patient. A range of demographic, historical and treatment data was recorded. These included direct questions to classify into one of four groups in the ACR Steinbrocker functional class:

I Completely able to perform usual activities of daily living (self-care, work, leisure)

II Able to perform self-care and work activities, but limited in leisure activities

III Able to perform self-care activities, but limited in leisure and work activities

IV Limited ability to perform usual activities of daily living (self-care, work, leisure)

3.1.8 Analysis

All data was entered on a database (Filemaker 2.1) and analysed using Excel 3.0 (© Microsoft Corporation) statistical package software. Univariate analysis compared the demographic profiles of the three patient groups, and revealed significant associations between variables. Mann Whitney U test uncovered relationships between HAQ and alcohol use in the two groups with arthritis. In all cases, numbers are presented by category in cross tables.

Section 3.2 Study Two

3.2.1 An opinion poll measuring levels of agreement / disagreement with 8 statements relating to 7 mental disorders among the public in England and Wales was devised by members of the Changing Minds Committee (Crisp et al, 2000). I was a member of this Royal College of Psychiatrists' Committee (the late Professor Arthur Crisp was its Chairman), representing the Irish Division, and I took part in the discussions about which statements to adopt. These were based on a limited literature at the time (principally Hayward and Bright, 1997 and Byrne, 1997), and the discussions of focus groups convened and funded by the College. I examined all the focus group sessions as part of my contributions to agreeing the final 8 statements. The disorders had been decided by the terms of reference of that committee: its brief from the College was to address the stigma of all 7 disorders. In Ireland, the survey was also the product of committee - the public education committee (PEC) of the Irish Division, chaired by Dr Kate Ganter until 1998, then by me throughout 1999: field work was completed during May and June 1999. I took the lead on this, and it was my recommendation to add questions about Awareness, perceived Knowledge about the disorders, and to change some of the wording of questions. For example,

Irish respondents were asked about Alzheimer's and anxiety, not dementia and panic attacks respectively. It was also my recommendation to ask about addictions in a single stem, not separately. Having agreed the question set, I negotiated an unrestricted educational grant from Pfizer (Ireland) to fund the study by employing Lansdowne Market Research, Dublin 2. They carried out a topline analysis that gave percentages indicating responses, but they did not carry out Univariate, Multivariate, or Regression analyses. Richard Waring of Lansdowne, released the survey database file (Merlin software) which I converted to SPSS. All statistical work quoted in this thesis was carried out by me under the supervision by Dr Bob Blizard and Professor Paul Bebbington. Study Two used the same international terms (Alzheimer's dementia, depression, schizophrenia, anxiety, alcohol and drug misuse, and eating disorders) as used in the clinic and to teach students. These terms are cited in each of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (American Psychiatric Association, 1994) and the *ICD-10 Classification of Mental and Behavioural Disorders* (World Health Organisation, 1990).

3.2.2 Sample

This was demographically representative of all adults aged 15 and over in the Republic of Ireland (RoI) and those aged 16 and over in Northern Ireland (NI). In RoI 1,370 interviews took place at 70 sampling points, and in NI 1,141 people were interviewed at 15 sampling points. In the first instance, the head of household was approached, and if he/she declined or was not available, a second member of the household was interviewed. Demographic data was collected prior to the formal interview: this identified age, gender, marital status, social class, region, and (for RoI only) television stations received. No questions were asked which would identify the religion of respondents: this information could not have been safely obtained in NI.

3.2.3 Design

A cross-sectional survey based on a single face to face interview. This took place between June 25 to 29, 1999 in NI and between May 20 and 31, 1999 in RoI.

3.2.4 Instruments

A semantic differential method (Link et al, 2005) was used to provide a direct assessment of respondents' agreement with stereotypical statements. Eight of the attitudinal questions were modelled on a parallel survey carried out during 1998 in England and Wales (Crisp et al, 2000). The questions were based on a combination of literature review (principally, Hayward and Bright, 1997) and the results of work (unpublished) carried out by the Royal College of Psychiatrists with focus groups of members of the general public. The **information** parameters were:

- their beliefs about medical treatment: "with medical treatment, their condition can greatly improve", and
- beliefs about prognosis: the likelihood of recovery: "most people with that condition usually make a full recovery".

Intermediate parameters (**information / attitude**) were:

- aetiology: "they are not to blame for their condition", and
- control over illness: "if they really wanted to, they could pull themselves together".

The first two questions combine *confidence* in treatment with beliefs about prognosis. The latter two questions concern perceptions of *blame* on the individual for the emergence of the disorder, and its course. Corrigan (2000) defined controllability as "both that the person is responsible for the onset of the disease, and for coping with its effects". Within "they are not to blame", the possibilities include heredity, environment, and the random occurrence of mental disorder. **Attitude** questions were:

- identification with the person: "I think we can all feel like they do sometimes"

- empathy and real-world communication: "they are hard to talk to".
- perceptions about the person's behaviour: "they are unpredictable".
- perceptions about potential threat from the person's behaviour: "they are a danger to other people"

Throughout the interview, each of the questions was asked in relation to all six mental disorders: Alzheimer's dementia, depression, schizophrenia, anxiety, alcohol and drug abuse (as a single condition) and eating disorders. Questions were direct in that they tested the respondents' beliefs, not their thoughts about others' attitudes. Three types of positive response were sought:

(1) yes or no to **awareness** of / "ever heard of" X (X denoting one of six conditions) and to the question about **personal contact**: "know someone who suffers from X".

(2) a six-part Likert scale to measure **knowledge**: "know a lot about X; know something about X; don't know; know very little about X; know nothing about X; and no answer.

(3) a six-part Likert scale for all other questions: "strongly agree, agree, neither, disagree, strongly disagree and don't know / no reply". In order to avoid response set, at several points in the list, these were presented in reverse order. The exact statement is given at all points in the text.

3.2.5 Interviewers

These were employees of Lansdowne Market Research Limited, Dublin 2, trained to carry out market research in RoI and NI. They had no medical or psychiatric training.

3.2.6 Procedure

Fieldwork took place from May 20 to June 29, 1999. Face to face interview took place in the home of respondents, based on census of each jurisdiction.

3.2.7 Analysis Plan

3.2.7.1 All data collected was recorded onto a standard database. This information was subsequently converted into the SPSS programme, version 10.0 (SPSS, 2002). Data interpretation used SPSS as the only statistical package.

3.2.7.2 Univariate analysis was used to define the four demographics (age, gender, marital status and socio-economic group) for each of awareness, contact and knowledge. Where these yes-no differences (aware-unaware, contact-no contact and good-poor knowledge) reached significance, binary logistic regression provided odds ratios (OR) for each demographic group. Regression operations make it possible to define the potent demographic variables that determine each of awareness, contact and knowledge. Differences between locations were also of interest for univariate analyses and logistic regression: respondents in NI versus RoI and rural versus urban. These two parameters could also be compared between disorders. Because the unaware group may lack familiarity with, or object to, the six terms used (Section 3.2.1), or they may be making another point (that they do not wish to answer questions about X), we were not certain that they were 100% ignorant of each condition, and therefore did not include this group in the "poor knowledge" subgroup above: Figure 3.1. Although by definition, all who had personal contact with someone with a disorder are aware of that condition, we made no assumptions about their levels of knowledge. Univariate analyses measured associations with attitudes by Chi squared testing, and these relationships were explored with binary logistic regression to yield Odds ratios (OR).

3.3 Study Three

3.3.1 This study seeks to compare the knowledge of and attitudes to ECT of a range of health professionals and students from both medicine and nursing.

3.3.2 Sample

Medical and nursing students, and doctors and nurses in Ireland's two largest cities, Dublin and Cork, were invited to complete a one-page questionnaire. These were

anonymous, and all persons who received a copy were asked to fill in their answers even if they answered "don't know" on "no opinion" to some questions. In all cases, every sheet was returned, giving a 100% response rate. For each group, the papers were dated and marked to identify their location (Dublin or Cork), profession (nursing or medical), career stage (student or postgraduate) and speciality (psychiatry, surgery or anaesthetics). The same questionnaire administered to all students, psychiatrists and psychiatric nurses was also used to record responses of other health professionals, including those working in the specialities of anaesthetics: anaesthetists and theatre nurses.

3.3.3 Design

Cross-sectional study with a single A4 page questionnaire (Appendix Three) **prior to** a scheduled lecture for students (undergraduate / postgraduate); for professionals (theatre / psychiatric nurses and anaesthetists) before an academic presentation.

3.3.4 Instruments

3.3.4.1 Six questions were asked of all participants: all but the mortality question had a five point Likert scale with don't know or no opinion at its centre. At one side, the options were "strongly agree" and "agree", with "disagree" and "strongly disagree" at the other. In every question, the abbreviation ***ECT***, was used, but this was denoted to mean "ELECTROCONVULSIVE THERAPY". The exact wording was as follows:

- "Mortality rates from ECT: 3 in 100 treatments or more; 3 in 1,000; 3 in 10,000; 3 in 100,000 and 3 in 1,000,000 treatments or less"
- "ECT is usually given to patients against their will"
- "The majority of patients who have ECT will refuse to have the treatment again"
- "If it is used excessively, ECT can cause permanent brain damage"
- "In severe depression, ECT should be considered as a last resort"
- "ECT is not as effective as Antidepressant medication in the treatment of depression"

3.3.4.2 The first question (asked second last on the actual questionnaire) was a factual one about the numbers of ECT deaths per treatment. Studies have consistently placed the death rates as between 3 in 100,000 and 3 in 1,000,000 (Scott, 1994). The next two concerned patient choice, based on the facts of consent: most ECT is administered to consenting patients and 65% of patients who have had the procedure agree to future ECT prescription (Freeman and Kendell, 1980). A fourth question tested knowledge of ECT side effects, specifically the public's association between ECT and brain damage. Short-term memory loss is a recognised side effect of ECT, but research shows that there are no significant long-term deficits (Devanand et al, 1991), and depressed patients who receive ECT show better cognitive performances than randomly matched untreated people with depression (Taylor and Abrams, 1985). Coffey et al (1991) used brain magnetic resonance imagine to examine for any structural abnormalities before and after courses of ECT. They found no brain changes after ECT, but reported some structural abnormalities before any ECT application (Coffey et al, 1991). The last two questions (Box 3.2) are *attitudinal* ones: we know that many cases of severe depression (in older people, during pregnancy or the puerperium etc.) require prompt intervention, and that ECT has been shown to be more effective than medication (Durham, 1989; Scott, 1994; Olfson et al, 1998; Geddes et al, 2003).

3.3.4.3 A variation of the contact hypothesis (Section 2.7) would be to examine whether direct experience of observation (students), administration (psychiatrists) or the provision of assistance (anaesthetists and theatre nurses) the procedure of ECT was associated with different attitudes to the treatment. For nursing and medical students, respondents stated whether they had completed or were completing their formal psychiatric ward attachment: for both professions, this is a "hands-on" experience of psychiatric inpatients and includes mandatory direct exposure to a minimum of one ECT session. Of note, students attend the same ECT sessions in all three centres where the questionnaire was administered: there were no separate

ECT sessions for medical and nursing students. For all students, the questionnaire was distributed before any lecture on physical treatments in Psychiatry or on ECT in particular. For anaesthetists and theatre nurses, they stated whether or not they had assisted in ECT over the past year. For qualified theatre nurses and anaesthetic doctors, they indicated whether or not they had participated in ECT administration over the previous year. Questioning took place over 18 months in Dublin and Cork.

3.3.5 Interviewers

The A4 questionnaire was self rating, distributed by three people who instructed participants to answer all questions, even if it were to indicate "don't' know". Three people administered the survey: PB, BC and PH. PB and BC are psychiatrists, and during the study period were clinical tutors in University College Cork (PB) and University College Dublin (PB and BC). This work involved regular lectures to medical students (pre and post psychiatric placements), student nurses (pre and post psychiatric placements at the Cork University Hospital, Dublin's Mater Hospital and Dublin's St Vincent's Hospital), and qualified psychiatric nurses (based at one of the three hospitals). In addition, PB was a post-graduate tutor in psychiatry, and distributed the questionnaire to trainee psychiatrists in Dublin: two groups – one studying for part one and the other for part two of the MRCPsych – answered the questions. PH is an anaesthetist who used the opportunities of lectures to theatre nurses and regular academic anaesthesia meetings (in both centres) to consultants and trainees at SpR (specialist registrar) level to administer the questionnaire. He did so before any lecture lest the subject matter contaminate responses.

3.3.6 Procedure

In all cases, the questionnaires were administered to everyone before the lecture or case presentation, and collected between 5 - 7 minutes afterwards by PB, BC or PH. No questions were invited from respondents, none were answered, and in all cases the questionnaires were distributed and collected without comment.

3.3.7 Analysis Plan

All data was collected and recorded onto the SPSS statistical programme, and data interpretation used SPSS as the only statistical package. All six answers of Box 3.2 were divided into three groups: (1) incorrect response (e.g. strongly agree or agree with the correct statement) (2) no answer indicated or "no opinion" chosen, combined to "don't know" and (3) correct response (e.g. strongly disagree and agree). These were assigned the categorical variables of 2, 3 and 4 respectively. Univariate analysis was carried out yielding Chi Squared values with significance, p. This test also gave a linear-by-linear association by polycotonous regression to test for significant trends across the variables of incorrect, don't know and correct. Linear by linear association gives an indication of the trend across groups (1) to (3). Based on sample size and numbers of statistical operations, we estimated significance at $p < 0.001$ as indicating low likelihood of false positive results.

Chapter Four: **Results and Discussion of Study One**

Mental distress, physical stigmata and attitudes in people with skin and joint disease.

4.1 Aims and Hypotheses 1

4.1.1 (1) To recruit and record demographic and disease data in three groups: people with psoriasis, psoriatic arthritis (PsA) and rheumatoid arthritis (RA)

(2) To measure disease parameters in each group with five standardised instruments (Section 3.1.4).

(3) To examine the relationship of alcohol use to the course of psoriasis, comparing this to people with arthritis (RA and PsA groups)

(4) To record methotrexate (MTX) as a possible confounder of alcohol use

4.1.2 Hypothesis 1: in people with psoriasis, self-stigma (their negative attitudes) drives their psychological morbidity and excess alcohol use.

4.2 Clinical and demographic features of disease sub-groups

4.2.1 243 patients were interviewed: 90 had symptoms only of psoriasis, 84 had RA, and 69 had PsA, with both skin and joint involvement. The duration of psoriasis in the PsA group was longer than that in the psoriasis group. 68 psoriasis (75.6%) and 26 PsA patients (37.7%) had been previously hospitalized for treatment of psoriasis. There was a tendency to a greater proportion of females in the RA group, as would be expected from epidemiological data: (Table 4.1). The RA patients were also older than the PsA and psoriasis group, and had a longer duration of arthritis than the PsA group. Functional scores, as assessed by the ACR Steinbrocker functional class and the HAQ score, were worse in the RA group than in the PsA group. Most RA patients were in the worst ACR class, but less than half the PsA group met these criteria: (Table 4.1).

Table 4.1: Demographic and clinical details of patients with psoriasis, PsA and RA.

	Psoriasis	PsA	RA
No. of Patients	90	69	84
Age	39 (35)	45 (47)	59 (60)
mean (median)	± 16 (15-77)	± 12 (35-54)	± 13 (31-82)
± 1 std deviation			
(range)	*$p=0.004$	^ $p=0.0001$	# $p = 0.001$
Male: Female ratio	48:44	33:36	30:54
Duration of arthritis	n/a	117 (84)	144 (120)
months		± 94 (5-384)	±116(12-492)
ACR class III/IV	n/a	31(45%)	53 (63%)
HAQ score	0.1 (0)	0.7 (0.6)	1.1 (1)
	± 0.2 (0-1.5)	± 0.7 (0-2.7)	± 0.8 (0-3)
	*$p=0.0001$	^ $p=0.0008$	# $p=0.0001$
Duration of psoriasis	221(192)	183 (168)	n/a
months	± 149 (6-720)	± 109 (117-240)	
Psoriasis Disability	4.8 (4) ± 3.7 (0-	2.9 (1) ± 3.4 (0-12)	n/a
Index (7-70)	12)		
	*p=0.004		
Methotrexate	11 (12%)	35 (51%)	40 (48%)
Oral Corticosteroid	-----	12 (18%)	43 (51%)

*psoriasis compared to PsA, ^PsA compared to RA, # psoriasis compared to RA

Figures given as mean (median) ± 1 std deviation (range)

Similar rates of non-steroid anti-inflammatory drug (NSAID) and methotrexate use were observed for the RA and PsA groups, with a lower rate of methotrexate use in the psoriasis group: (Table 4.1). The RA group had a higher rate of steroid use than the PsA group. Similar rates of sulphasalazine, azathioprine and cyclosporin use were observed for RA and PsA: (Table 4.1).

Table 4.2: Mental distress and alcohol use in patients with psoriasis, PsA and RA.

	Psoriasis (n=90)	PsA (n = 69)	RA (n = 84)
mPLSI	4.8 (4) ± 3.7 (0-12)	2.9 (1) ± 3.4 (0-12)	1.7 (0) ± 2.9 (0-12)
	*$p=0.001$	^$p=0.004$	#$p=0.0001$
HADS	7.8 (8)	7.8 (8)	5.4 (5)
Anxiety	± 4.6 (0-18)	± 4.1 (1-17)	± 3.9 (0-16)
score		^$p=0.0002$	#$p=0.001$
HADS	4 (3.5)	5 (5)	4.7 (4)
Depression	± 3.2 (0-12)	± 3.1 (0-13)	± 3.7 (0-16)
score	*$p=0.04$	^$p=NS$	#$p=0.03$
Alcohol	14 (13) ± 13 (0-72)	8.2 (4) ± 10.8 (0-54)	5.9 (3) ± 8.1 (0-36)
(units)	*$p=0.002$		#$p=0.001$

*psoriasis compared to PsA, ^PsA compared to RA, # psoriasis compared to RA
Figures given as mean (median) ± 1 std deviation (range)

4.2.2 The distribution of peripheral joint disease in PsA was polyarticular (4 or more joints) in 47 patients and oligoarticular (3 or less) in 16 patients. Fifteen patients had spondylitis and/or sacro-ileitis (9 with peripheral joint disease; polyarticular = 7, oligoarticular = 2). The type of psoriasis in PsA patients was predominantly plaque: 59 patients (85.5%). Others had guttate (3 respondents), erythrodermic (5), pustular (1), and unstable / plaque (1). The type of psoriasis in the psoriasis group was also predominantly plaque 64 (71.1%) though there more patients with guttate (10), erythrodermic (7) and pustular (3), and unstable / plaque psoriasis (8).

4.3 Comparison of physical disease severity and psychological morbidity

4.3.1 Direct comparisons were made between the PsA and RA groups: (Table 4.2). As noted above, the RA group was significantly older, with a slight preponderance of females. As expected, the PsA patient group tended to have skin involvement longer

than joint symptoms: (Table 4.2). There were no significant differences in the means and standard deviations of illness duration, and similar proportions had been treated with methotrexate (MTX): (Table 4.2). The severity of functional impairment was significantly higher in the RA group as measured by HAQ, and this was also reflected in the higher proportions of RA patients who were assigned ACR classes 3 and 4 (Section 4.1.7). Given the older age and female preponderance of the RA group (Table 4.1), and the established associations between RA and depression (Section 2.3), the prevalence of depressive symptoms is high in the RA group. Table 4.2 shows no significant differences between RA and PsA for the depression component of HADS: the younger and less "arthritic" PsA group have similar depressive scores. There are significantly higher anxiety scores in the PsA group, and Spearman's correlation coefficient between the anxiety score of HADS and the PLSI is $r=0.402$, $p=0.0001$. The HAQ score correlates with the HADS depression score: rho, $r=0.436$, $p<0.0001$, but HAQ has no association with its anxiety component: $r=0.02$, $p=0.7$. Stigma scores, as measured by the mPLSI, were significantly higher in the PsA than the RA group, and higher in those people with psoriasis only than the PsA group: Table 4.2.

4.3.2 Comparisons were made between the PsA and psoriasis groups: (Table 4.2). PsA patients were older with significantly longer skin disease duration. As expected, PsA HAQ scores were higher, but the skin only group registered loss of function on the HAQ. Psoriasis-related disability as measured by the PDI was higher in the skin only group. Both had high depression scores, with the PsA group higher, just reaching significance: (Table 4.2). The HADS depression scores for the psoriasis-only group were not significantly different from those for RA. All people with psoriasis had higher anxiety scores than the RA patients. Anxiety scores were similar, and this was despite

higher PLSI and PDI scores (more impairment) in the psoriasis group. Examination was therefore made of the specific stigma questions of the PLSI: Section 4.5.

4.4 Alcohol and psoriasis

4.4.1 There are no significant differences between RA and PsA for alcohol consumption, although there is a trend for more alcohol in the latter group: (Table 4.2). Patients with psoriasis-only have higher alcohol consumption levels than patients with PsA: (Table 4.2). All three conditions are presented in Table 4.3, and we confirm the association between psoriasis and increased alcohol consumption set out in Table 2.3.

Table 4.3: Alcohol consumption (units / week) and relationship with joint disease

	PsA	Psoriasis	RA
Alcohol consumption	4 (0 – 13)	12 (3 – 20)*	3 (0 – 8)
HAQ score	0.63 (0.1 – 1)	--	1 (0.4 – 1.7)*
Values are median (range). * $p < 0.05$ Mann Whitney U test.			

Table 4.4 shows the drinking patterns of the 85 patients currently taking methotrexate. 69 people (81.2%) are either abstinent or consume below 10 units. Only 7 patients (8.2%) are consuming above recommended guidelines. Table 4.5 shows moderate drinking in the psoriasis group who take MTX, but no differences in the RA group.

Table 4.4: Alcohol consumption and methotrexate use: all patients on MTX

Units of alcohol	RA (n=40)	PsA (n=34)	Psoriasis (n=11)
0-10	33	27	9
10-21	4	3	2
>21	3	4	0

Table 4.5: Alcohol consumption in patients taking methotrexate: all MTX patients

	RA	PsA	Psoriasis
On methotrexate	6 (2.8) + 1.3	6.7 (4) + 9.1	3 (0) + 5.9
Not on MTX	5.9 (3) + 8	9.6 (4) + 12.2	16 (14) + 13.4

4.4.2 With regard to self-reported alcohol use, RA and PsA patients show the same pattern, with less than 10% drinking more after illness onset: (Figure 4.1). One in three arthritis patients cut back on alcohol after illness onset, though 43% of people with PsA say drinking makes their joint symptoms worse. This should be seen in the context of no alcohol differences between RA and PsA (Table 4.2) and less drinking by PsA patients on MTX (Table 4.7). We identified a paradoxical response to psoriasis: 29.7% people drank more alcohol after illness onset, despite the fact that 34.4% of psoriasis patients and 26.2% of PsA patients believe it makes skin problems worse. It is possible that the 29.7% who increased weekly intake may explain the alcohol excess: Table 4.2.

Table 4.7: Alcohol consumption since onset of disease.

Alcohol consumption since onset of **psoriasis**

	Less	Same	More
Psoriasis (n=91)	14 (15.4%)	50 (54.9%)	27 (29.7%)
Psoriatic arthritis (n=64)	16 (25%)	39 (60.9%)	9 (14.1%)

Alcohol consumption since onset **arthritis**

	Less	Same	More
Rheumatoid arthritis (n=80)	31 (38.7%)	41 (51.3%)	8 (10%)
Psoriatic arthritis (n=65)	21 (32.3%)	39 (60%)	5 (7.7%)

Effect of alcohol on **psoriasis**

	Better	No effect	Worse
Psoriasis (n=90)	1 (1.1%)	58 (64.4%)	31 (34.4%)
Psoriatic arthritis (n=65)	0	48 (73.8%)	17 (26.2%)

Effect of alcohol on **arthritis**:

	Better	No effect	Worse
Rheumatoid arthritis (n=78)	8 (10.3%)	57 (73.1%)	13 (16.7%)
Psoriatic arthritis (n=63)	4 (6.3%)	44 (69.8%)	15 (43%)

4.5 The nature of psychological symptoms in psoriasis

Four questions related to subjects' perception of stigma: Box 3.1. The total possible score was 8, and the cut-off for "stigmatised" was 3 or greater out of 8. The cut-off was believed to indicate actual day to day impact on people with psoriasis: while some might assign a maximum 2 points to "feeling self-conscious", to score 3 or more, there must be behavioural consequences. The scoring system (Box 3.1) gave no points for difficulties "to a slight degree", and a score of 3 or more ("stigmatised") indicates stress to a moderate degree with at least three of the activities listed, or a great deal of stress in one, with (at least) moderate stress in another activity. Correlation between mean alcohol consumption and total score was modest: r=0.13, p=0.04.

Figure 4.1 Alcohol amount since onset of skin and/or joint disease: percentages

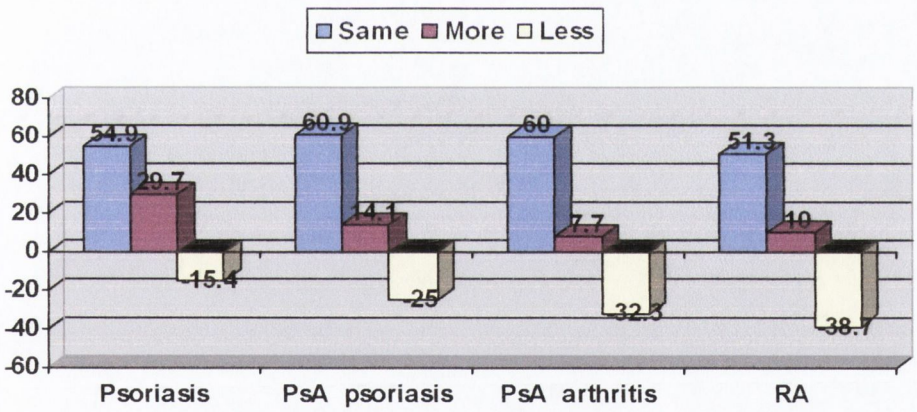
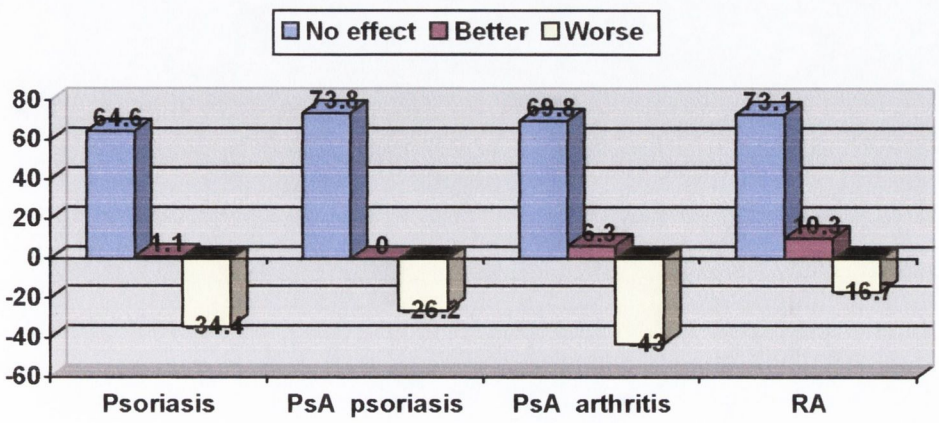


Figure 4.2 Subjective effect of alcohol on skin and/or joint disease: percentages



The psoriasis patients are divided into stigmatised (score >3 / 10) and not stigmatised (<3 / 10), and associations with alcohol (typical week and last week) and psychological morbidity were examined. For both alcohol measures, psoriasis patients with higher stigma scores drink significantly more than people who perceive low or no stigma (Table 4.8). Figure 4.1 shows a linear relationship to increased alcohol after disease onset in the whole group: skin only subjects increase the most, joint only the least, and skin and joint subjects lie intermediate to these. Despite 34% and 26% saying it makes skin problems worse, only 15% psoriasis and 25% of PsA subjects cut down, in other words, less cut down alcohol that thought it made it worse. The significant association between anxiety and stigma score (Table 4.8) could reflect that the questions of the mPLSI are also a proxy for anxiety.

Table 4.8: Comparison of stigmatised and nonstigmatised people with psoriasis

	Less than 3 stigma points out of 8	More or equal to 3 stigma points out of 8	Significance
Alcohol last week	9.54	12.7	p<0.01
Alcohol typical week	10.2	13.8	p=0.001
Anxiety score	6.6	9.0	p=0.001
Depression score	3.6	5.1	p= NS

4.6 Discussion of Study One

4.6.1 In Study One, people with psoriasis had severe forms of skin disease, where 64 out of 90 had been hospitalised for skin disease. Comparison between the RA and PsA groups must also be seen in the context of age and gender differences between the

two groups: the RA group was older with a higher proportion of females (Table 4.1). Any group which has more women and older persons will be expected to have more depressive symptoms (Goldberg and Huxley, 1992). There are established associations between depression and RA (Section 2.2.3), and meta-analysis showed rates of depressive disorder of two to three times as common in patients with RA than the general population (Dickens et al, 2002). In Study One, the RA group had more arthritis disability (as measured by HAQ: Table 4.1) than the PsA group. Despite these potential confounders, we found no statistical differences in HADS depression scores between the RA and PsA groups: (Table 4.1). With regard to anxiety scores on HADS, the PsA group had significantly higher scores than the RA group, and this morbidity seems unlikely to be due to their arthritis alone: (Table 4.1). Comparison between the Psoriasis and PsA groups showed no age or gender differences (Table 4.1), but the PsA group had a nonsignificant trend of longer duration of skin symptoms. Psoriasis and PsA patients had similar anxiety scores, but with depression scores significantly ($p=0.04$) higher in the latter group, perhaps reflecting the combination of skin and joint disease.

4.6.2 In the total group, HAQ and depression correlate well: $r=0.436$, $p<0.0001$. In her meta-analysis of depression in RA, Dickens (2002) established a relationship between low mood and pain levels. Sharpe et al (2001) have measured the importance of psychological factors (initial depressive symptoms, coping strategies and beliefs about illness) as outweighing the effects of physical illness markers (pain and disability) in a prospective study of RA and depression. Study One found no relationship between HAQ and anxiety symptoms: Section 4.2.1. In parallel to the RA associations, the anxiety component of HADS and the PLSI (as proxy measures of psychosocial morbidity) correlate closely: $r=0.402$, $p=0.001$. Harvima et al (1996) used different measures (Table 2.2) in their study of 38 patients with psoriasis vulgaris and reported

stress (sic) levels at 42%, with low mood symptoms in 37%. One study found a combination of higher anxiety in psoriasis with strong subjective beliefs that life events and stress were the most common means of dermatological relapses (Fried et al, 1995). Fortune et al (2002) also found high levels of anxiety (see Table 2.2), but this was not predicted by age, gender, family history, age at onset or duration of psoriasis; rather 28% of the variance in anxiety was predicted by illness perception. Study One replicates the finding of higher anxiety levels in patients with psoriasis (e.g. Harvima et al, 1996; Fortune et al, 2000; Jowlett and Ryan, 2002), confirms established links between depression and arthritis, and identifies both psychological syndromes in people with PsA. Study One shows that despite far more psychosocial impairment (as measured by PLSI and PDI) in the psoriasis than the PsA group, there are similar levels of increased anxiety.

4.6.3 Study One confirmed that a major determinant of anxiety in people with psoriasis is visible skin disease: Table 4.2 showed higher anxiety levels in people with skin over joint disease, despite having less functional impairment. The mPLSI may be measuring a particular form of anxiety (Section 4.5). Another possible mechanism is that increased stigma in skin patients leads to anxiety, with self-medication on alcohol. PsA patients have the highest "makes it worse" scores, 43%, perhaps due to a combination of the dysphoric effects of alcohol and its short term effect on anxiety levels. Baughman and Sobel (1970) added an intriguing finding to the literature about physicians' and patients' perceptions in rating psoriasis severity. While patients ranked "embarrassment over one's appearance" as the most severe factor, their dermatologists rated this as the lowest. This study assigned primarily anxiety to skin conditions, and low mood to joint disease, thus confirming the paradigm of Findlay-Jones and Brown (1981): Section 2.3.1. This paradigm is represented by Figure 4.3. Subsequent to the completion of this

study, two studies quantified the degrees of anxiety in people with psoriasis. Fortune et al (2000) scored 38% within one standard deviation of the worry score for patients diagnosed with generalised anxiety disorder. Richards et al (2001) administered the HADS to 115 people with skin-only psoriasis and found probable anxiety in 43%, with depression in 10%. They could explain 44% of the HADS variance not by disease severity, but by perceptions of stigma (Richards et al, 2001).

4.6.4 With regard to alcohol consumption, the majority of all patients (51.3% to 60.9%) did not change drinking pattern because of physical disease and a larger majority (greater than two thirds) say that alcohol has no effect (Figure 4.1). One third of arthritis patients cut down on alcohol after arthritis onset: these are probably MTX patients, and more cut down that thought it made it worse. RA patients are not drinkers, and being on MTX has no significant association with mean alcohol levels: (Table 4.6). There are no differences in alcohol use between the RA and PsA groups, but *psoriasis only* patients drink more than RA controls (Table 4.1). Figure 4.2 identifies a paradoxical response to psoriasis: 29.7% people drank more alcohol after illness onset, despite the fact that 34.4% of psoriasis patients and 26.2% of PsA patients believe it makes skin problems worse. Study One replicates the findings of Poikolainen et al (1994) who reported that after psoriasis onset, there is an increase in alcohol intake, smoking (a possible confounder here: Table 2.3) and negative life events. In reporting increased anxiety associated with greater stigma in the context of alcohol consumption increase *after* illness onset, Hypothesis 1 is proven.

4.7 Limitations of Study One

Study One is a once-off cross-sectional survey. The psoriasis group studied was at the severe end of the spectrum: 68 psoriasis (75.6%) and 26 PsA patients (37.7%) had been hospitalised for treatment of psoriasis. Table 4.1 showed important differences in

the RA group: they were older, with more females, more often on (depressogenic) steroids and had higher severity of arthritis by HAQ. In Study One, psychological morbidity was measured with the Hospital Anxiety and Depression Scale (HADS). Since its development over 20 years ago (Zigmond and Snaith, 1983), this instrument has been well-tested in populations with physical illness and has been used most frequently in those psoriasis-depression studies which used a valid psychometric instrument (Table 2.2). However, HADS is a screening not a clinical instrument, and its findings can be questioned. In addition, any associations reported do not prove causality.

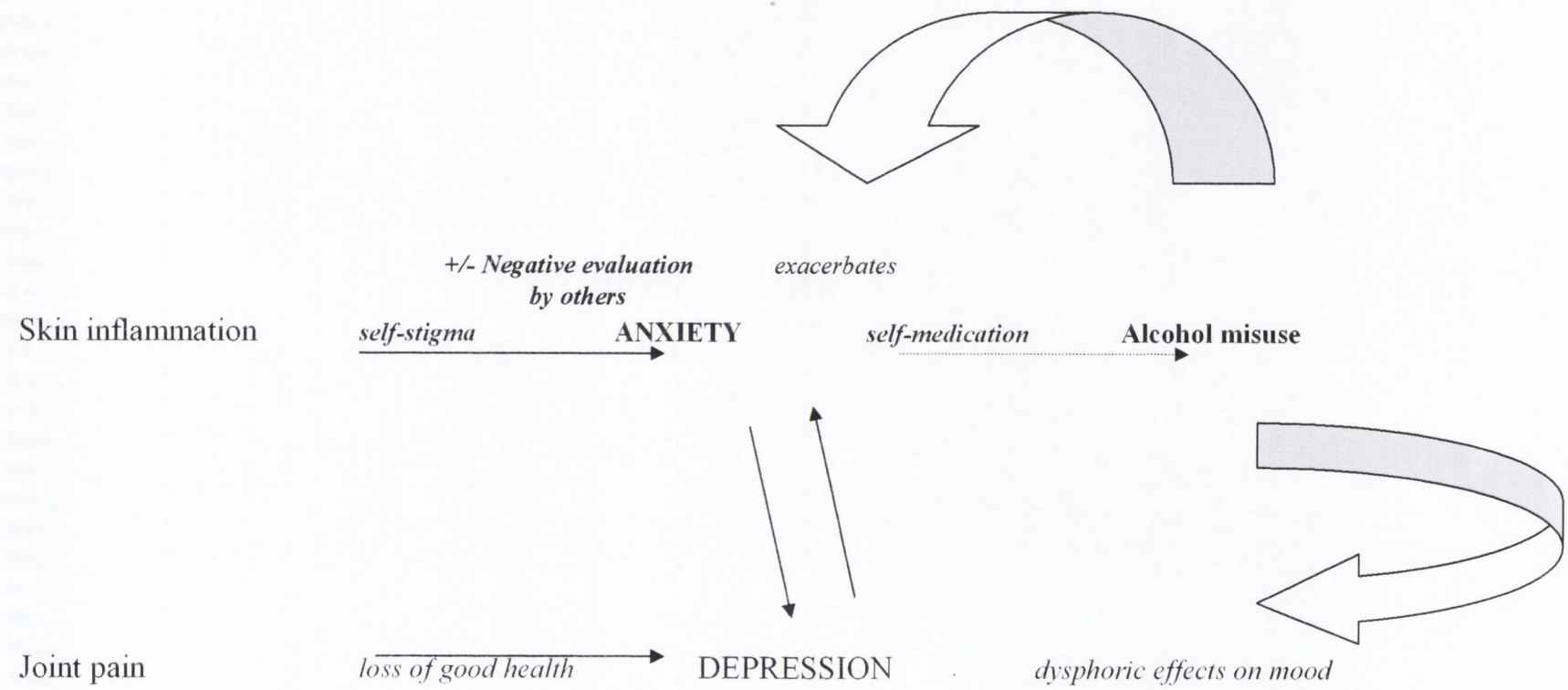
4.8 Implications for people with psoriasis

4.8.1 A UK community study (Rea et al, 1976) has measured the prevalence of psoriasis as between 1 and 2% in the urban population of Lambeth, south London. In Northern England, O'Neill and Kelly (1996) reported a point prevalence of 1.3%. Despite the presence of this common, chronic relapsing and irritating hyperproliferative skin condition, only 17% consult their GP and 3% attend a dermatologist, leaving 80% who seek no medical advice (Hunter et al, 1982). Adverse psychosocial sequelae of psoriasis are universal findings (Table 2.2), including in an Irish population (Ramsay and O'Reagan, 1988). Study One confirms high levels of psychological morbidity in psoriasis with the theoretical possibility that the mechanisms are stigma-driven (Section 4.6). In particular, anxiety was highly prevalent in our population. Recently, O'Leary et al (2004) have hypothesised that patients' beliefs that stress is causal in psoriasis is in itself a major determinant of their psychological distress but not skin disease. Anxiety is a treatable disorder, for many without recourse to medication (Enright, 1997), and its amelioration will secure less skin morbidity and better outcomes in people with psoriasis (Doran et al, 1985; Folks and Kinney, 1992). Stigmatising aspects of psoriasis have been neglected by researchers (Section 2.3) and Study One corrects this, in addition to

challenging the blaming assumptions about alcohol use in the condition (Table 2.3). Ginsburg and Link (1989) carried out the first study (51 hospital and 41 out-patients) of the role stigma plays in the course of psoriasis, and among their many positive findings, reported that visible skin bleeding was the strongest predictor of perceived stigma and despair. Our findings support the hypothesis that a major determinant of stress levels is visible skin disease (Table 4.2). Independent of the judgements of others, self-stigma is a cause of "social" anxiety and measurable psychological morbidity. Negative experiences (stigma) from familiar people or strangers may contribute: the public may react with awkwardness when they see skin abnormalities (as unsightly or even infectious), but feel pity for people with deformed joints (Figure 4.3).

4.8.2 Psoriatic arthritis (PsA) is a chronic inflammatory disease of skin and joints that occurs in approximately 5-17% of patients with psoriasis with, a prevalence of 0.3% (Veale and Fitzgerald, 2002). Although the psychosocial morbidity of psoriasis and RA has already been deemed equal in one study (Scharloo et al, 1998), the psychological impact of developing both skin and joint disease (i.e. PsA) has not been defined until this study. Study One defines high and comparable psychological morbidity in psoriasis and RA (Table 4.2), where PsA stands intermediate between the two disorders. Despite our expectation that less extensive skin lesions in the PsA group (significantly lower PDI) would be linked with less anxiety in PsA, there were no significant differences (Table 4.2). This may reflect the interactions between anxiety and depressive symptoms (Goldberg and Huxley, 1992), which have not been accounted for in the theoretical model of Figure 4.3. There is some support for this depression-anxiety interaction in that the PsA and RA groups are identical in mood symptoms and alcohol use. Study One advocates thorough psychosocial assessment and treatment of people with all three medical conditions, with particular attention to hidden anxiety symptoms.

Figure 4.3 Possible pathways of psychological morbidity in people with psoriasis and arthritis



4.8.3 Study One confirmed the alcohol-psoriasis association (Table 2.3) but raised the possibility that anxiety levels, driven by stigma, lead to excess alcohol consumption (Section 4.6). Some early studies, for example Zacharie and Segaard (1973), believed that frequent findings of abnormal liver pathology in people with psoriasis were caused not by alcohol misuse (or sensitivity to its use), but by the psoriasis itself. Two studies (Delaney and Leppard, 1974 and Grunnet, 1974) supported this finding. The literature on alcohol-psoriasis was initially confusing (Table 2.3), but Wolf (1999) provides a useful critique of the difficulties inherent in this area of research:

1. widespread disagreements over definitions of alcohol misuse and alcoholism
2. several other lifestyle choices (notably cigarette smoking, but including caffeine intake, diet and drug misuse) are correlated with alcohol consumption. All are potential confounders in researching associations with alcohol.
3. the emotional distress associated with psoriasis could be caused by alcohol use
4. alcohol use in psoriasis could represent an epiphenomenon: excess alcohol use may be a response to a combination of anxiety and low self-esteem in psoriasis.

This fourth option, namely that social influences such as stigma could drive alcohol use as "self-medication" (Table 1.1), was not considered when the alcohol-psoriasis link was first made (Texon, 1950), and rarely since then (Table 2.3). Smart and Wegner (1999) set out the cognitive and interpersonal effects that occur as a result of keeping stigma a secret. Study One supports alcohol excess in psoriasis as an epiphenomenon – a response to the combination of anxiety (fear of negative evaluation) and low self-esteem of psoriasis. How any increase in alcohol consumption in psoriasis is likely to interrelate with other psychological sequelae of the disease has not been previously addressed. Higher anxiety in psoriasis raises the possibility that some of their increased alcohol use may be to relieve anxiety, that is, "self-medication": (Table 1.1 and Figure

4.3). Alcohol is a major cause of psychological morbidity and mortality, and over 100 physical diseases, including skin disorders, have been associated with its misuse (Farber and Nall, 1994). Although alcohol will reduce anxiety symptoms during consumption (it is a CNS depressant), its sequelae will include additional difficulties such as rebound anxiety, avoidance behaviour, depressed mood, and increasing tolerance, even dependence. Alcohol misuse is complicated: Kalvi (1985) could explain 90% of the alcohol variance in psoriasis patients by family history alone: Table 2.3. An alternative explanation of excess alcohol use in psoriasis (which ignores Study One's finding that there is a minority who believe that alcohol makes the skin lesions worse) is that alcohol medicates psoriasis directly. Zhang et al (2002) carried out in vitro work charting that alcohol leads to vasodilatation, increased vessel permeability, enhanced neutrophilic granulocyte migration and infiltration: these usually lead to epidermal cell proliferation (Zhang et al, 2002). Arnetz (1985) speculated that psoriasis patients have different psychoendocrine profiles than controls. Devrimci-Ozguven et al (1999) discuss three possible??? for the interaction of stress and psoriasis: (1) the effects of disease processes via the pituitary-adrenocortical axis (2) stress-related immunomodulation and (3) changes in neuropeptides. Study One cannot speculate underlying mechanisms, but gives some explanation of anxiety comorbidity and problem drinking (Figure 4.3).

4.8.4 Study One recommends screening for anxiety and/or low mood using the self-rating HADS, with direct enquiry about alcohol use. Clinicians should assess consumption in the context of medication use (MTX for example) and psychological symptoms, provide appropriate support where it is needed, and institute targeted prevention strategies. People with psoriasis and their physicians need to be aware of alcohol misuse, but to understand its complex relationship to psychosocial morbidity (Figure 4.3). Unmasking psychological symptoms in skin conditions has financial

implications of identifying psychiatric morbidity without the resources to "fix" it (Cooper, 2004). But other stigma-driven consequences arise when symptoms are labelled "psychosomatic" or "functional", given even these terms now have mostly pejorative connotations (Looper and Kirmayer, 2004). In a comparison study of physical and functional illness (n=238), perceived stigma – measured with the EMIC instrument of Weiss et al (1992) of Section 1.3.3 – was higher in the latter group (Looper and Kirmayer, 2004). Comparing physical with mental health, Lai et al (2000) report far less stigma in cardiac than psychiatric patients. In reporting high levels of mental distress in people with psoriasis and / or arthritis, Study One is identifying a clinical population who have sought help for physical symptoms, but whose mental ill-health is undiagnosed and untreated. Research on physical illnesses of higher priority, for example, ischaemic heart disease, has consistently identified poorer outcomes in physical and psychological morbidities of patients who also have psychological symptoms (Muehrer, 2002). Some early studies of mood symptoms in skin disease failed to link psoriasis with mental distress (Table 2.2). Fava et al (1980) found more anxiety in people with urticaria (a transient inflammatory skin condition with intense itching) than with psoriasis, and Hardy and Cotteril (1982) did not detect any low mood in their psoriasis subjects. It is unlikely that these two studies could be replicated, or validated with reliable psychometric tests. Although Section 2.2.1 sets out the achievements of Gupta and Gupta (1987, 1989, 1993 & 1998) in making the link between psoriasis and depression, and this was a welcome advance on its association only with alcohol (Table 2.3), the focus on depression may have led to the relative neglect of anxiety symptoms. Of 19 studies (Table 2.2), only a few studies subsequent to Study One (beginning with Richards et al, 2001) support findings of higher anxiety symptoms in psoriasis. There are countless other medical conditions where psychological symptoms worsen their

course – in many cases the active process is stigma, the second illness, and clinicians are unwise to wait for their patients to present or complain.

4.9 Implications for health professionals and students

Finally, there are lessons from Study One for students, allied health and social care professionals, public health and service providers. The division of arthritis and psoriasis into two separate psychological syndromes, with prominent depression and anxiety symptoms respectively (Figure 4.3), is a helpful distinction for these groups. These two psychiatric syndromes have clinical and epidemiological links (Goldberg and Huxley, 1992), and have a bidirectional relationship. This parallels debates within psychiatry about dual diagnosis patients (comorbidity of psychiatric illness and substance misuse). Mental health professionals need to engage and treat patients without judging them or their social contexts:

> "Psychiatry is not a narrow medical speciality. It is, if anything, the widest of the medical specialities in that it applies the entire bio-psycho-socio-cultural spectrum of mental health care endorsed by the World Health Organisation (WHO), to which some other branches of Medicine only give lip service. In WHO terms, psychiatrists and psychiatry should address not just the pathological lesion, but also the functional impairment, the social disability, and the communal or cultural handicap" (Rosen, 2001).

Chapter Five: Results and Discussion of Study Two

Section 5.1 Awareness, Contact and Knowledge

5.1.1 Percentages who were aware of each disorder, had personal contact with someone who has this disorder, and have good perceived knowledge ("know a lot" and "know something") are set out in Figure 5.1. Depression and the addictions score highest in all three parameters, and schizophrenia has the lowest scores in each (Figure 5.1). For all six conditions, everyone who knew someone with the disorder had awareness for that disorder (Figure 2.3). Awareness levels were also calculated excluding contact, but the difference was always less than 3%, the margin of error for this sample: 90.7%, 94.2%, 86.3%, 86.7%, 95.4% and 87.9% respectively. Univariate analysis defined the effects of four demographic variables (age, gender, marital status and socio-economic group) and location (RoI or NI, urban or rural) for each of awareness, contact and knowledge. Where these yes-no differences (aware-unaware, contact-no contact and good-poor knowledge) reached significance, binary logistic regression provided odds ratios for each demographic variable: (Tables 5.1 to 5.3). Because the unaware group may lack familiarity with, or object to, the six terms used, or they may be making another point (that they do not wish to answer questions about a disorder), we were not certain that they were 100% unaware of each illness, and did not include this group in the "poor knowledge" subgroup (Table 5.3).

5.1.2 Awareness levels were almost always over 90% of the sample, with some variation between conditions (Figure 5.1). Even allowing for demographic and income differences between countries, respondents from NI were between 1½ and 3 times more likely to be aware of every disorder (Table 5.1). Awareness shows an inverted U-shaped relationship to age (lowest at the extremes of age), significant ($p<0.001$) in six conditions: Figure 5.2. Age was a significant determinant of dementia, schizophrenia and eating disorders awareness (Table 5.1). When regression took account of the other three demographic variables, age had no associations with

depression awareness, and barley reached significance in just one age group about anxiety (Table 5.1). Older adults were significantly less aware of the addictions and eating disorders, and with the exception of substances, women have higher awareness than men. Allowing for other variables, married respondents were more aware of every disorder (Table 5.1). Social class has a direct association with awareness, with higher income groups significantly more aware of every condition (Table 5.1). Where awareness is low, the associations pertain: lower paid and single people, men, and those at the extremes of age. For three disorders there were no significant differences between Greater Belfast and the predominantly rural rest of NI, but RoI urban dwellers had three times schizophrenia and anxiety awareness over their rural compatriots, higher again for the other disorders (Table 5.1).

5.1.3 About one fifth of the sample had **contact** with someone with one of the six disorders, with considerable variation across the disorders (Figure 5.1). Contact with someone with schizophrenia was the lowest of all disorders, and this follows the same demographic as awareness, but has no rural associations (Table 5.2). An inverted U-shape curve describes the relationship between contact and age, but age has no significant associations with addictions' or eating disorders' contact when corrected for other demographics (Table 5.2). Although marriage has significant associations with contact, regression of being married when corrected for the other three variables fails to reach significance in any condition. Higher social class is associated with more contact with the exception of addicts (Table 5.2). Allowing for all four demographics, NI respondents are between 1.3 and 1.8 more likely to have contact. It was possible to identify respondents with personal contacts having more than one disorder: 792 people (31.5%). Their demographic profile paralleled that set out in Table 5.2. There were significantly more women (35.2% Vs 27.3% men; $\chi2=18.0$, df=1, $p<0.001$), middle-aged people (33% Vs 25% young persons; $\chi2=16.3$, df=4, p=0.003), married people (33.6% Vs 29.2% single; $\chi2=5.7$, df=1, p=0.017), members of ABC1 (36.8% Vs 28.4% nonABC1; $\chi2=19.6$, df=1, $p<0.001$), and

residents from NI (35.2% Vs 28.5% RoI; $\chi 2=13.2$, df=1, $p<0.001$). There were significant urban-rural differences for multiple contact in NI (38.9% rural Vs 30.9 urban; $\chi 2=7.9$, df=1, p0.005), but there was no RoI urban-rural differences.

5.1.4 Respondents who had personal contact were more likely to rate their **knowledge** as good, and about two thirds people with personal contact (with each of the six conditions) rated their knowledge as either knowing a lot or knowing something. In descending order, the highest levels of good knowledge among people with personal contact are: the addictions (78.1%), depression (70.8%), eating disorders (70.7%), Alzheimer's dementia (66.6%), anxiety (64.3%) and schizophrenia (60.7%). The effects of younger age were less striking with more knowledge only in eating disorders, and less knowledge in anxiety alone (Table 5.3). Women report greater knowledge of mental disorders than men do, but there were two disorders where there were no associations (Table 5.3). Married people had more knowledge only of dementia and depression. Across all disorders, higher social class predicted greater knowledge (Table 5.3). Only one cross border difference, addictions' knowledge, achieved significance. Urban-rural differences occurred in RoI only and were confined to three disorders, where urban respondents have 1½ times more knowledge than their rural compatriots (Table 5.3).

Section 5.2 Attitudes

5.2.1 Responses to 8 attitude questions were placed into three groups: agree, disagree and a third group that combined "don't know", no answer given and no opinion (middle Likert option). Where negative attitude occurs, this group is analysed against the rest of the sample, that is, the contrary answer plus the combined don't know group. Between a fifth (depression and the addictions) and a third (dementia, anxiety and eating disorders) of respondents comprised the don't know group about the two outcome questions: Figure 5.3. This proportion was higher about the PTT question, and all results presented below should be viewed in this context (Figure 5.3). **Confidence in medical treatment** was strong, where less than 10% held

negative views with the single exception of dementia: Figure 5.4. Pessimism about the benefits of schizophrenia treatment was higher in people who knew someone with the disorder, with a corrected odds ratio of 0.6 (0.4 to 0.8). Full recovery was not thought possible in schizophrenia (26.6%) or the addictions (20.7%), but these two groups had no associations with the four demographics. People in NI were more optimistic here than RoI respondents, with odds ratios (corrected for four demographics) of 1.2 (1.01-1.42) and 1.41 (1.16-1.72) respectively. **Blaming** an individual for each disorder did not exceed 10% in the first four conditions (Figure 5.4). When the high blame scores for the addictions and eating disorders were analysed, only one demographic was significant in that the youngest group was significantly more blaming about eating disorders than over 65s, 29.7% and 15.7% respectively. There were no other associations with blaming attitudes, with the exception of NI where the corrected odds ratio for blaming an addict was 1.3 (1.11-1.53). Over one fifth of respondents endorsed pull-themselves-together (PTT) beliefs about depression and anxiety, higher again for the last two disorders (Figure 5.4). There were no cross border differences, but men were more likely to have PTT views about depression: corrected odds ratio 1.42 (1.17-1.72). Younger people have higher PTT totals than other age groups: OR 1.56 (1.12-2.22). Other demographic associations were lower income (non-ABC1) respondents' PTT beliefs about addicts, corrected odds ratio 1.19 (1.01-1.41), and rural location. PTT beliefs about depression were less likely in rural RoI but higher in rural NI: OR of 0.67 (0.45-0.89) and 1.47 (1.1-1.96). Of note, there were no other rural PTT differences, but rural NI was more blaming about anxiety, the addictions and eating disorders: OR 1.84 (1.39-2.44), 1.84 (1.44-2.34) and 1.58 (1.23-1.58) respectively.

5.2.2 Answers to the final four questions are set out in Figure 5.5. Similar no opinion scores are seen on these questions as for the first set: between 20% and 40%. About 15% had no **empathy** with someone who is anxious or depressed, rising to over half the respondents for schizophrenia, addictions and eating disorders (Figure 5.5). For

the former two disorders, contact significantly improved empathy, but it has no effect in schizophrenia and eating disorders. In each of dementia and the addictions, lack of empathy was higher in people with contact: corrected odds ratios of 1.4 (1.17-1.69) and 1.8 (1.46-2.19) respectively. The second social distance question, that they are **hard to talk to**, elicited higher negative responses in all but schizophrenia (Figure 5.5), and these are analysed as Table 5.4. Men were more likely to judge this negatively in depression, but women endorsed communication problems more in schizophrenia (Table 5.4). Marital status had an influence only in anxiety, but here, married people were more likely to believe the person was hard to talk to. In contrast to previous trends, ABC1 respondents and NI residents were more likely to judge communication problems in schizophrenia (Table 5.4). Middle-aged respondents perceived more communication difficulties in dementia, but they compared well to younger respondents who held negative views in relation to eating disorders (Table 5.4). In four conditions, significant rural-urban differences in NI were found, where rural respondents were more negative, but this trend is reversed across the border where RoI rural residents were more positive (Table 5.4). Contact was associated with significantly greater perceptions of hard to talk to across every condition except anxiety (Table 5.4). People who know someone with an eating disorder were 1.4 times more likely to hold negative views about their ability to communicate, and this rose to 2.2 times in relation to Alzheimer's. The two social distance questions were also analysed in relation to good knowledge of each disorder. For the empathy question (we cannot feel like they do), the good knowledge group was associated with more empathy only for the first four conditions. There was no association for eating disorders, and the good knowledge of addictions group were associated with less empathy with addicts ($\chi 2=9.8$, $p<0.001$). The good knowledge of addictions group were also associated with higher perceptions of communication difficulties ($\chi 2=64.7$, $p<0.001$), and the same is true for good knowledge of dementia and

depression: (χ2=141.7, p<0.001 and χ2=33.8, p<0.001 respectively). By contrast, those with good knowledge of schizophrenia were associated with more positive beliefs about difficult communication: (χ2=77.4, p<0.001).

5.2.3 Beliefs about **unpredictability** and **danger** varied widely across the disorders (Figure 5.5). Women had significantly higher perceptions of unpredictability than men in dementia and eating disorders. Being married was also associated with higher levels of unpredictability beliefs about Alzheimer's, but there were no other associations with marital status, nor any for age on this question. Members of ABC1 had significantly higher unpredictability beliefs in Alzheimer's, depression and schizophrenia. The only cross border differences about unpredictability occurred in schizophrenia and the addictions, with higher beliefs about this in NI. All associations remained significant following exclusion of contact, disorder by disorder. The good knowledge group for each condition had significantly higher unpredictability scores in all six disorders. Because addictions and schizophrenia had the worst profiles for danger and distance (Figure 5.5), demographic determinants and associations with other parameters were analysed in detail. There were no associations between danger perceptions and age, gender or marital status. In schizophrenia alone, ABC1 respondents had significantly higher perceptions of danger: (χ2=13.4, p<0.001). NI respondents had higher perceptions of danger in schizophrenia and the addictions, with correct odds ratios of 1.92 (1.62-2.28) and 1.56 (1.27-1.9) respectively. Contact with someone with schizophrenia had no effect on perceptions of danger, but contact with an addict increased this perception: corrected odds ratios 1.53 (1.21-1.94). Having good knowledge of each disorder is significantly associated with higher perceptions of danger in schizophrenia and the addictions: (χ2=49.2, p<0.001 and χ2=55.0, p<0.001 respectively). The two concepts, danger and unpredictability, appeared to overlap in schizophrenia and the addictions, where each disorder had high Spearman's correlation coefficient: Table 5.5. For the other four conditions,

these correlations were significant, but modest. Both risk questions correlated well with the two social distance questions, but only in relation to schizophrenia and the addictions: Table 5.5. High levels of blaming and PTT attitudes had poor correlations in the common mental disorders and the addictions (Table 5.5). Because danger and empathy appeared to correspond in all but Alzheimer's and eating disorders (Figure 5.5), their correlations are also presented for depression and anxiety. There were no relationships between risk and empathy here, but even where danger perceptions are low (19% and 7.7% in depression and anxiety respectively), beliefs about difficult communication correlated significantly with danger perceptions (Table 5.5).

5.2.4 The effects of **contact** were analysed for all 8 questions in each of six disorders. There were only two significant associations for the first four questions (24 attitudes). People with contact were less likely to believe in a good outcome in schizophrenia: 37.5% versus 48.5% without contact, $\chi 2=18.7$, df=1, $p<0.001$ yielding a corrected odds ratio of 0.57 (0.44-0.75). Secondly, those in contact with someone with an eating disorder were more blaming: 28.5% versus 22.6% without contact, $\chi 2=6.1$, df=1, $p<0.01$ yielding a corrected odds ratio of 1.33 (1.03-1.71). There were more associations for the latter four questions, and these are set out as Table 5.8. **Good knowledge** had no significant effect on 5 out of a possible 24 negative attitudes. It improved empathy in depression, but otherwise good knowledge was associated with more negative attitudes in 18 cases (Table 5.6). Because of the strong negative effect of good knowledge on attitudes, the contribution of contact was also tested allowing for knowledge (Table 5.6). Contact had no effect on danger beliefs in any condition, or on empathy in three. With regard to beliefs about unpredictability, for every disorder except anxiety, contact with someone who had it was significantly associated with greater perceptions of unpredictability. Overall, contact was associated with more negative attitudes in eleven comparisons, and more positive attitudes in two. Contact improved empathy only in depression and anxiety (in the

absence of any other effect on attitudes to anxiety), but *increased* perceptions of communications difficulties and unpredictability across five disorders. Those with any contact (53.5%) were significantly more likely to have negative attitudes to all four questions about the two "danger" disorders, schizophrenia and the addictions.

5.2.5 Scores were assigned to the empathy, communication and unpredictability questions (1 for strongly disagree; 2, disagree; 3, neither; 4, agree; and 5, strongly agree with the negative statement) to assign a **total social distance** (TSD) score for each disorder. TSD was calculated within groups based on good knowledge, personal contact and danger perceptions: (Table 5.7). Mean TSD was lowest in the common mental disorders and highest in addictions, with schizophrenia in second place. TSD has no associations with better knowledge or contact in depression, anxiety, and eating disorders. For the three other disorders, good knowledge and contact always results in higher TSD scores. When the effects of contact are excluded, better knowledge of dementia and schizophrenia increases respondents' desired social distance from people with these conditions: (Table 5.7). Without exception, danger beliefs were always associated with increased TSD: (Table 5.7). The relationships between TSD and the four demographics and urban-rural location were tested with linear regression. There were no demographic or location associations with TSD in dementia, depression, anxiety or eating disorders. Older age, corrected for the three other demographics, was a determinant of higher TSD in schizophrenia and the addictions: Beta 0.09 (0.06-0.23), $t=3.4$, $p<0.001$ and 0.1 (0.08-0.22), $t=4.4$, $p<0.001$ respectively. Women also had significantly higher TSD towards addicts: 0.08 (0.14-0.47), $t=3.6$, $p<0.001$. There were also urban-rural differences, with rural dwellers having higher TSD: 0.17 (0.42-1.03), $t=3.4$, $p=0.001$ and 0.15 (0.37-0.85), $t=4.9$, $p<0.001$ in schizophrenia and addictions respectively.

Section 5.3 Hypothesis testing

5.3.1 Table 5.8 sets out the profile of each disorder in relation to eight parameters. Awareness is high in general, but low in schizophrenia and anxiety. In the context of

their relative lack of life experience, younger people are less likely to have contact with people who have the first four disorders, and women more likely to know someone who has dementia, depression or an eating disorder (Table 5.2). Contact levels parallel the relative prevalence of each condition and knowledge parallels these to some extent (Table 5.8). As expected, the common mental disorders have the least stigma, and the addictions and schizophrenia have the highest connotations of danger: unpredictability in the latter conditions (Table 5.5) equates with danger. Blame is strong for addicts and people with eating disorders, and dementia, though blameless, attracts higher pessimism and social distance. As a summary of findings, Table 5.8 confirms **Hypothesis Two**, the public differentiates six mental disorders: each has a unique profile based on awareness, knowledge and key attitudes. The demographic profile of people with negative attitudes (Table 5.9) cannot be constructed in the same way Table 5.8 profiles each disorder. As a potential confounder, contact was eliminated from analyses, but his effected no change on the demographic determinants of attitudes. The demographics of contact (in particular single and rural respondents) are different to those for awareness, nor do they correspond to the groups with poor knowledge: Table 5.9.

5.3.2 The effects of demographic factors on the three key variables are presented as Table 5.9. Knowledge does not follow the demographics of awareness and contact. Poor knowledge is associated with lower income, rural or RoI residence and to a lesser extent, male gender. Based on the analyses of Tables 5.6 and 5.7, with the single exception of anxiety, good knowledge is significantly associated with more negative attitudes: **Hypothesis Three**, as it relates to Study Two, is not proven.

5.3.3 There is no evidence to support therapeutic pessimism among this sample, save for the outcome of dementia (Figure 5.4). Blame is a factor only in relation to eating disorders (21.5%) and the addictions (48.8%). PTT levels were higher but still modest and had demographic associations, men and lower income, only in depression (Section 5.2.1). From analysis of the associations (Tables 5.5 and 5.7),

the strongest driver of stigmatising attitudes is fear (Section 5.2.5), not beliefs about aetiology or outcome: **Hypothesis Four** is proven.

5.3.4 Section 5.1.4 identifies positive effects of contact on improving respondents' perceived knowledge, thus partially supporting the final hypothesis. Other results challenge the contact hypothesis: contact increased perceptions of danger from people with schizophrenia and addicts (Section 5.2.3) and made respondents more blaming and more pessimistic about outcome (Section 5.2.4). It is not just that Study Two frequently failed to find associations (only two out of a possible 24 questions: Table 5.6), but in almost every instance where there were significant, contact made negative opinions worse. **Hypothesis Five**, as applied to Study Two, is unproven.

Section 5.4 Discussion of Study Two

5.4.1 Study Two provides Irish users and professionals with useful data on the **awareness** of six disorders. Although the definitions of knowledge and contact in Study Two need to be more rigorous (Section 5.5), the awareness first approach has been justified: we are interested as much in the *don't knows* and *don't-want-to-knows*, as in "stigmatisers". Many public attitude studies have neglected these populations, to quote just one example, the recent Swiss study of Lauber et al (2004b): "the response rate (to telephone contact of a random sample) was 63%. Main reasons for refusal were 'no interest' (39%), 'disapprove of opinion polls' (20%) and 'no time' (15%)". In this instance, how meaningful is studying community integration in two thirds of the population? Consideration of the 3 to 12% of the population who are not aware of the six conditions (Section 5.1) must be made before examining differences based on demographics. In advertising terms, mental illness has low product recognition, with high "turn off" potential. In schizophrenia – described as the greatest challenge in stigma (Sartorius, 1997) – Study Two found lack of awareness as high as 16% of single men and 27% of farmers. It is worth noting that most respondents, that is, anyone under 55 years' old, will have lived most of their lives in a society (RoI or NI) where community treatment of mental illness has become the accepted norm.

Community psychiatry was implemented on both sides of the border without adequate financial resources or consultation with local communities. Responses of apathy or elective hostility ("don't ask") are understandable in this context: change strategies need to echo Leff's strategy of "getting the community to care" (Leff, 2001).

5.4.2 Unexpected findings were that being married has no independent effect on **contact**, and that NI residents had 1½ times the contact rates of their southern neighbours (Section 5.1.3). The profile of a person more likely to have direct contact (higher social class, female, middle aged, NI) corresponds closely with the higher knowledge person: (Tables 5.2 and 5.3). Further, contact with more than one person predicts significantly better knowledge for every condition: (Section 5.1.3). Phillips (1966) speculated about the relationship of knowledge to stigma: "the increased ability of the layman to identify certain behaviours as mental illness does not necessarily imply changes in the way he will act toward persons suffering from mental disease". Murphy et al (1993) found no association between contact and attitudes in a rural RoI sample. The levels of contact in that study were low (30.3% with a family member), and do not compare with respondents with any contact in Study Two or one recent Irish survey where 73% of respondents reported personal contact (Mental Health Ireland, 2003). In a larger census-based study of attitudes to depression, McKeon and Carrick (1991) (as Study Two) failed to prove the contact hypothesis. Only one RoI study, Barry (1994), found positive effects of contact on negative attitudes. Study Two can not claim to negate the contact hypothesis as it did not determine the nature of personal contact, not least if this contact was first-hand experience. The question arises whether the weak positive effects of contact Study Two in anxiety and depression could be explained by "contact" here meaning *first hand experience* in respondents who experienced the common disorders of anxiety and depression *in themselves*.

5.4.3 The two conditions which receive the highest public profile in RoI and NI, Alzheimer's dementia and depression, score the highest **knowledge** scores, with

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beliefs that bulimia was "self-induced" (58.0%), with similar numbers in relation to anorexia nervosa (51.5%), compared to 9.9% for schizophrenia (Fleming and Szmukler, 1992). Strong views about self-infliction have also been reported in the addictions (Ghosde et al, 1986 and Ritson, 1999). Brickman et al (1982) drew a useful distinction between attribution of responsibility for a problem and attribution of responsibility for solution, based on their review of the psychology literature on when help produces changes in recipients, and the social psychological literature on the help-givers. Allowing for the exclusion of the *unaware* group and the *don't knows*, depression scores one fifth, anxiety one quarter, eating disorders one third and the addictions well over one half of respondents. As a rule, Study Two reports rural respondents more blaming than their urban counterparts, but this must be qualified in that blame is a rare negative attitude. Murphy et al (1993)'s rural Ireland sample (n=155) recorded responses to mental illness, unspecified: "(the) person should pull himself together" 31.6%, and "had themselves to blame" 9.1%, and here, negative attitudes correlated directly with age. The findings of Study Two (positive attitudes in older people and negative attitudes in the young) undermine this ageist consensus. Currin et al (1998) have reported an increase in positive attitudes to mental health and help-seeking in older US adults, compared to 20 years ago. In Western societies, older people may have had low familiarity with mental health issues in surveys of thirty years ago, but this no longer applies to contemporary populations.

5.4.6 Analyses of **risk perceptions** must be seen in the context that "unpredictability" means different things to different people and for different disorders (Magliano et al, 2004), but there is good evidence to support a strong relationship to danger in schizophrenia and the addictions: (Table 5.5). As expected, perception of danger in Alzheimer's and anxiety have weak correlations with communication difficulties. Given that danger appeared specific to schizophrenia and the addictions, beliefs about danger were also tested in relation to confidence in treatment and outcome, and not only do these opinions coexist, but they correlate significantly (Table 5.5).

There are no demographic predictors of danger except higher income in schizophrenia: (Table 5.9). Lower class has been regarded as a stigma predictor since Hollingshead and Redlich (1958). However, parallel to the rejection of the older person stigmatiser stereotype (Section 5.4.5), aside from negative beliefs about the two danger conditions, people on lower incomes are a priori "stigmatisers".

5.4.7 There are many advantages to **profiling** each disorder separately (Table 5.8):

- these data do not validate stereotypes. Rather it acknowledges the evidence that in the Western world, people avoid or discriminate people against mental illness on the basis of identifyable stereotypes (Blizard, 1970; Angermeyer et al, 2003).
- profiles of each condition set out its key challenges: danger, empathy etc.
- these six disorders are clinical terms: findings about knowledge, or areas of misinformation, could be used by clinicians to modify help-seeking behaviour
- an integrated model of each disorder will help to explain why subpopulations delay help-seeking or decline treatment: women for alcohol misuse (Schober and Annis,1996), or some ethnic groups for schizophrenia (Sohler et al, 2004)
- agreement with stereotypes explained an additional 10.6% of the variance in attitudes in a large Dutch public attitude study (van 't Veer et al, 2006).

Brief discussion of the three most stigmatised disorders is merited. Schizophrenia has the poorest overall public profile of all. While Study Two found some pessimism about its outcome, in the absence of other drivers, high endorsement of dangerous stereotypes is likely to be the dominant factor in increasing SD here. The combination of low awareness and contact reflects its high SD scores. The addictions have high familiarity and contact, but blame and fear are high (Table 5.6). Blizard (1970) found higher rejection of alcoholics than for any other condition, even a vignette of paranoid schizophrenia that included implicit mention of violence. Caetano (1987) identified contradictions in the public's attitudes to alcoholism: 91% agree it is an illness, but 40% believe "they drink because they want to" and 24% would not want an alcohol

treatment unit near to where they live (NIMBYism: Section 1.2). Endorsement of the disease model was related to class, but social rejection and other negative attitudes were not (Caetano, 1987), a finding Study Two replicates. Eating disorders are characterised by high levels of blame (Figure 5.4): in the absence of other explanations, blaming "silly rich girls" may drive the high SD scores found.

Section 5.5 Limitations of Study Two

5.5.1 Despite Rabkin's assertion in Section 2.4.1, there are concerns about the inconsistent relationship of this research on stated attitudes to actual behaviour. It is worth stating a major limitation of this type of research, first commented on by Buchnill in 1860: "noble and just sentiments are in everyone's mouth, but personal antipathy is in everyone's heart" (quoted by Schull, 1993). Some methodological choices are likely to further underrepresent the levels of stigma in Study Two: forced choice (closed) questioning and that knowledge was self-rated by respondents. A number of additional limitations apply to Study Two. The primary comparison here is with Crisp et al (2000 & 2005). There are several differences between the two studies:

- The ONS study separated alcohol from drug misuse, but Study Two did not. We considered both conditions under the general heading of addiction.
- The ONS study asked questions about "dementia" (unspecified). We took the decision, following discussions with the Alzheimer's Society of Ireland (ASI) to specifically enquire about "Alzheimer's dementia". ASI had run a number of public education campaigns North and South of the border, prior to data collection. Findings of awareness of Alzheimer's dementia consistently above 90% justified this decision.
- The ONS study (Crisp et al, 2000) asked participants for their views on "panic attacks" whereas our questions were about "anxiety" *unspecified*. We believed only a minority of Irish respondents would claim knowledge of panic disorder, and further, that the brief of the College Campaign (noted above) was to address the stigma of anxiety disorders in general, not panic disorder in particular.

Having acknowledged these differences between Crisp et al (2000), the Irish study has two potential advantages over the UK survey:

(1) Questions about awareness were included to draw distinctions between being uninformed and ill-informed (Section 2.5). In reporting profiles of unaware and don't know groups, we defined additional target groups for interventions.

(2) Levels of knowledge were not tested in the UK study.

This and the UK study neglected personal experience of mental ill health. Link et al (2005) criticised SD measures as evoking desirable responses with poor correlation to behaviour. Study Two's measures of SD have not been validated unlike the "flawed" SD measures of previous studies. At the time of the survey (1999), neither RoI nor NI were ethnically diverse societies, and (for obvious reasons in NI), religion was not recorded for analysis. Generalisation of Study Two's findings to multicultural European societies, or the more prosperous Ireland of today, cannot be made.

Section 5.6 Implications for service users

5.6.1 High public confidence in psychiatric treatments and good outcomes for each disorder are set out above, and the case has been made that their confidence is higher than professionals'. Where pessimism exists, for example low confidence in improvements in Alzheimer's dementia following social and physical treatments, this can be addressed relatively easily. In real world studies, *patients* have far less confidence in treatments for the other five disorders, and this predicts drop-out rates from clinical care (Edlund et al, 2002). In this regard, we can contrast the public's unrealistic high expectations with the low expectations of service users. At some point in the journey from member of the public to service user, comes disappointment and conflict. Some parallels have been drawn elsewhere with the advertising industry, and the analogy is useful here. When an advertiser hypes their product, the result is high sales and high profit, but unsatisfied consumers whose enthusiasm is short-lived. In the mental health arena, it is important to realise (drawing on Study Two) that at any new patient clinic, clinicians are meeting people with high, unrealistic

expectations. By contrast, patients who are returning to the clinic with actual experience of mental health treatment, have less confidence in treatments than the GPs and specialist staff who treat them (Carr et al, 2004). A sound therapeutic alliance is to everyone's advantage, and to achieve this, professionals need to steer a course between grandiose claims and a counsel of despair where recovery is never expected (Edlund et al, 2002). Perceptions of danger define schizophrenia and the addictions, and although Study Two separated the two, dual diagnosis (someone with schizophrenia and substance misuse) is common, and NIMBYism is activated more by the antisocial consequences of drug or alcohol misuse than by psychosis.

5.6.2 Over 50% of mental illness is undiagnosed and untreated (Kessler, 2001). At some point, people with mental health problems have to reconcile what happens to them (symptoms) with their previously held attitudes: they may deny, self-medicate, oppose treatment or decline to adhere over time, or refuse care (Table 1.1). In most cases, the demographic profile for low awareness (single people, rural dwellers and people with lower incomes) matches people more likely to develop mental health problems. In relation to rural dwellers, Hoyt et al (1997) linked increased negative attitudes to less willingness to seek mental health care if needed. Help-seeking for depression has been linked to self-stigma and perceptions of a stigmatising response from health services (Barney et al, 2006). The demographics of contact also play a role in determining social networks, and therefore outcomes, of users: Section 7.6.

5.6.3 Attitude studies provide schemata for the cognitive components of cognitive-behavioural therapy (CBT). Holmes and River (1998) list CBT strategies that counter external stigma and self-stigma: Socratic questioning, hypothesis testing, cognitive restructuring, exposure and activity planning. Drawing on Link's "coping orientations" (Section 1.4.4), they discuss response options: social withdrawal, indiscriminate or selective, and social action. The best option can be decided *case by case*, and they advocate decision-making strategies based on *cost-benefit analyses*: identify all possible costs and potential benefits of disclosure of the stigma. Although their

approach makes instinctive clinical sense, what is striking is the dearth of evidence-based studies for these interventions (Holmes and River, 1998). Recent reconceptualisations of psychosis (Garety et al, 2000) allow for the possibility that stigma-mediated events play a role in relapses of psychosis through the ways these events are evaluated. Appraisal of events by someone with psychosis is influenced by reasoning and attributional biases (e.g. jumping to conclusions), dysfunctional schemata of self and the world, and isolated or adverse environments. This approach to psychosis is compatible with the theoretical basis for stigma (Chapter 1), and will provide opportunities for research that will translate into better clinical outcomes.

Section 5.7 Implications for health professionals and students

There is a temptation is to view public opinion as something "out there" or abstract. Patients hold many strong beliefs about mental illnesses and the people who get them, and clinicians / students need to be aware of these, and their own prejudices. Lauber et al (2004b) administered the same questionnaire to psychiatrists and the public: there are no differences between the two groups in their SD scores, but the public are more prepared to work with someone with mental illness than professionals are. These findings are interesting in MHL terms: the people with the most knowledge / MHL are just as stigmatising, and in some cases have higher SD scores. Studies indicating professional antipathy support the notion of professionals as reservoirs of stigma – a consistent finding of service user research into discrimination (Section 1.2). Obstacles to help-seeking are a combination of self-stigma and perceived stigma: both appear directly related to the degree of mental health care – highest when there is contact with psychiatrists (Barney et al, 2006), perhaps explaining some of the contradictions in the literature: Section 1.4.3.

Figure 5.1: Awareness, Knowledge and Contact of six mental disorders in Ireland: Percentages

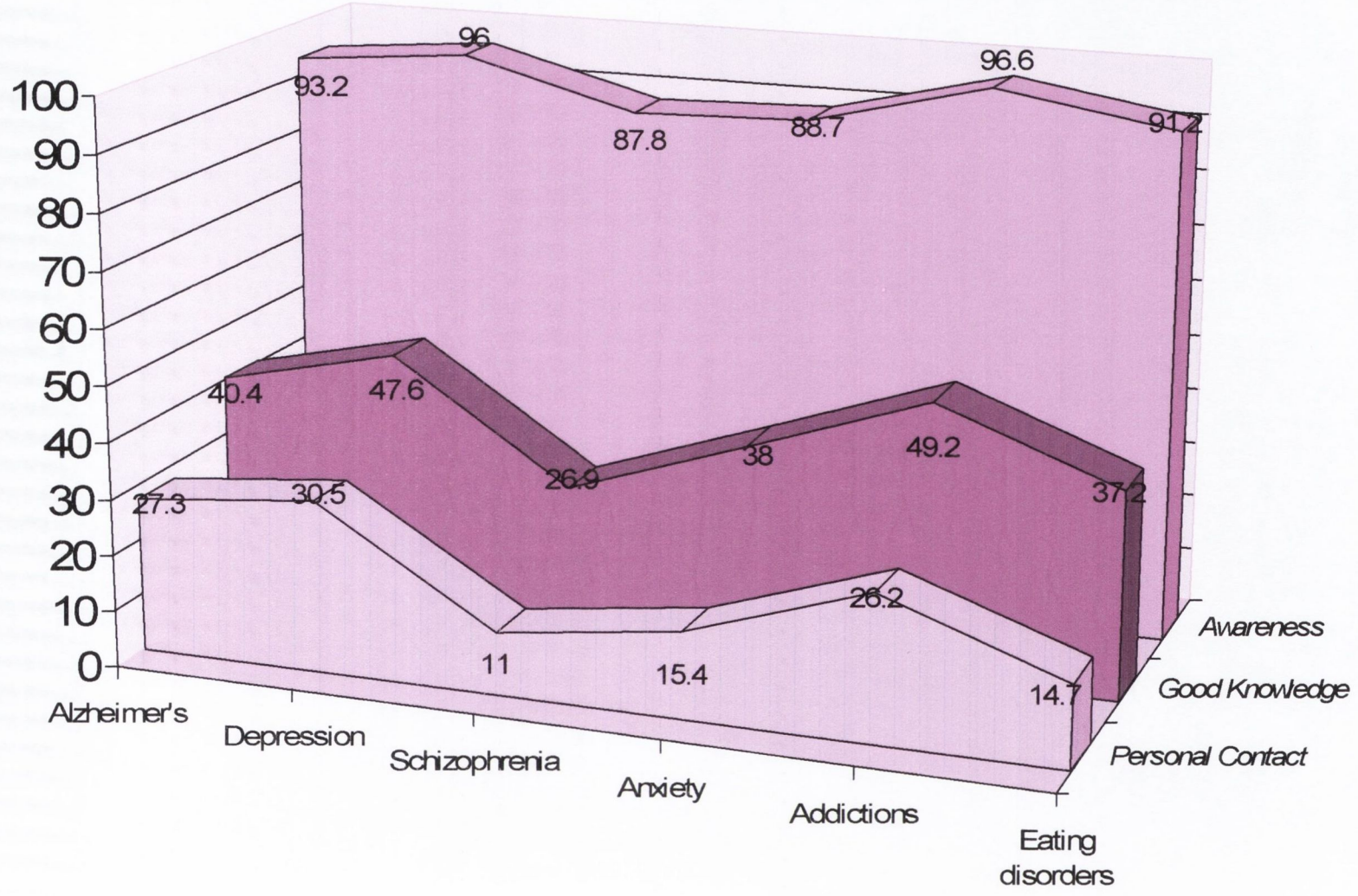


Figure 5.2 Age (horizontal axis) and percentages who are Aware of each disorder

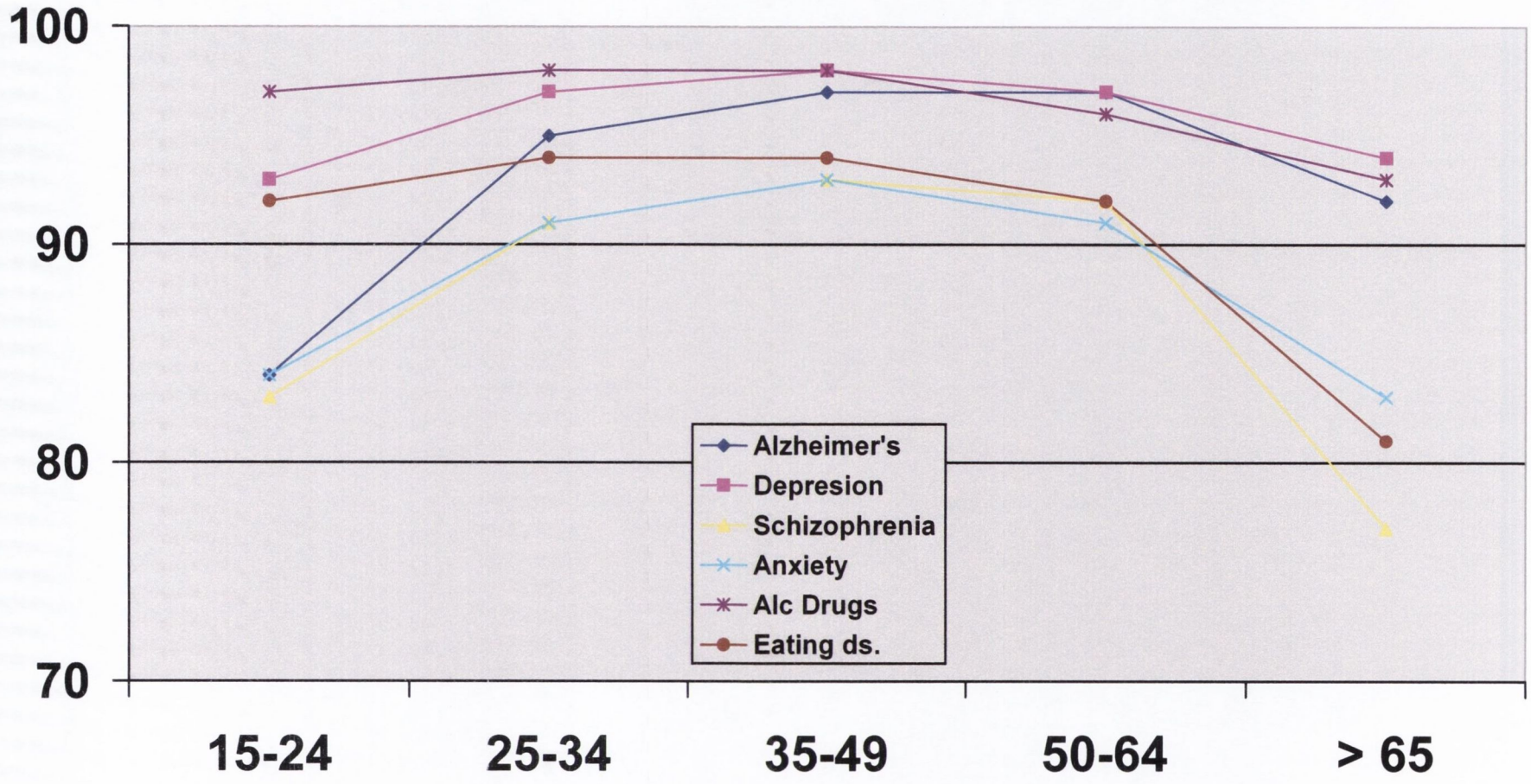


Figure 5.3: Percentages indicating **neither opinion or don't know** to five attitude questions. Base: aware of disorder

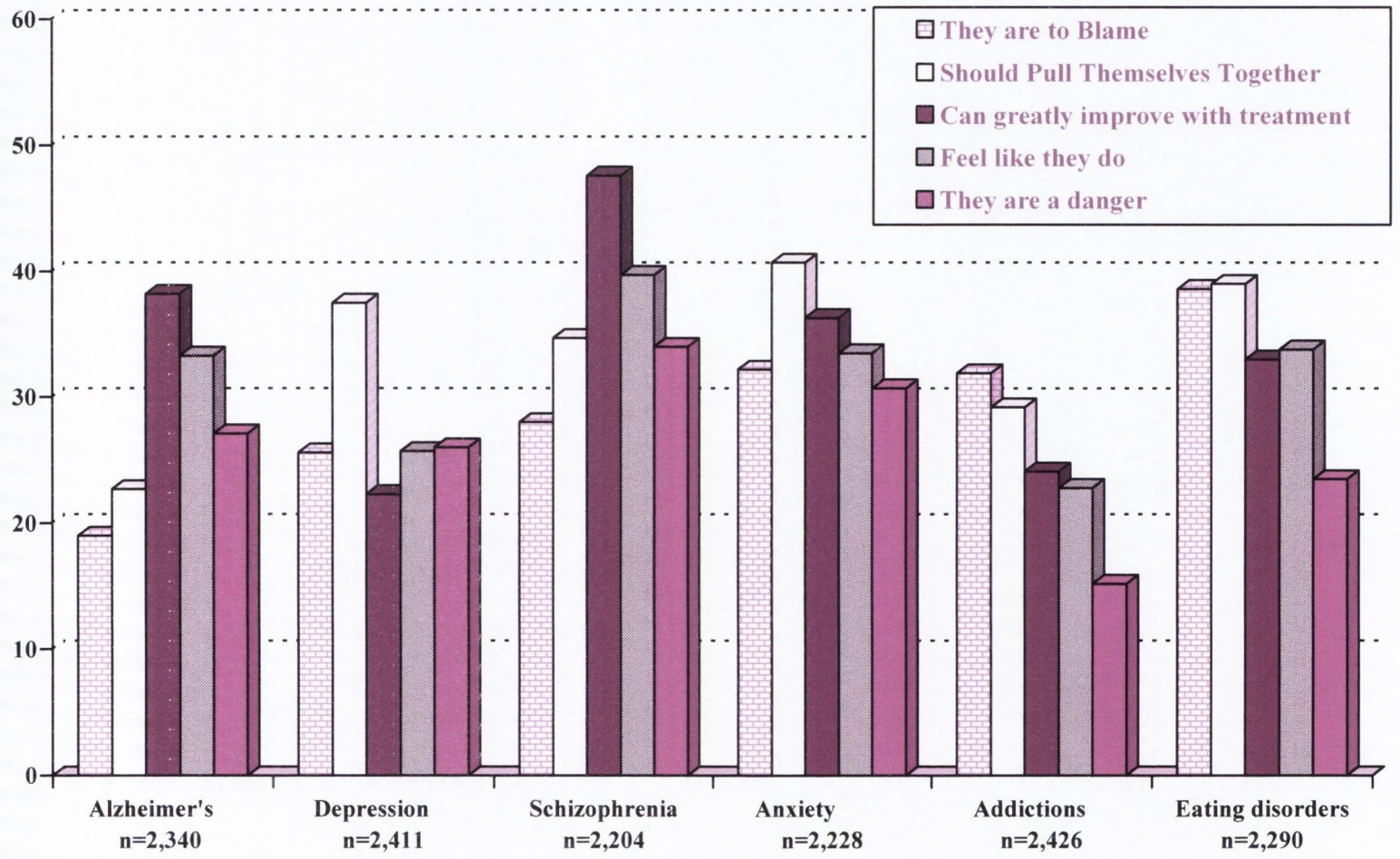


Figure 5.4: Opinions about **Aetiology** and **Outcome** of six mental disorders in Ireland: percentages. Base: aware of each disorder.

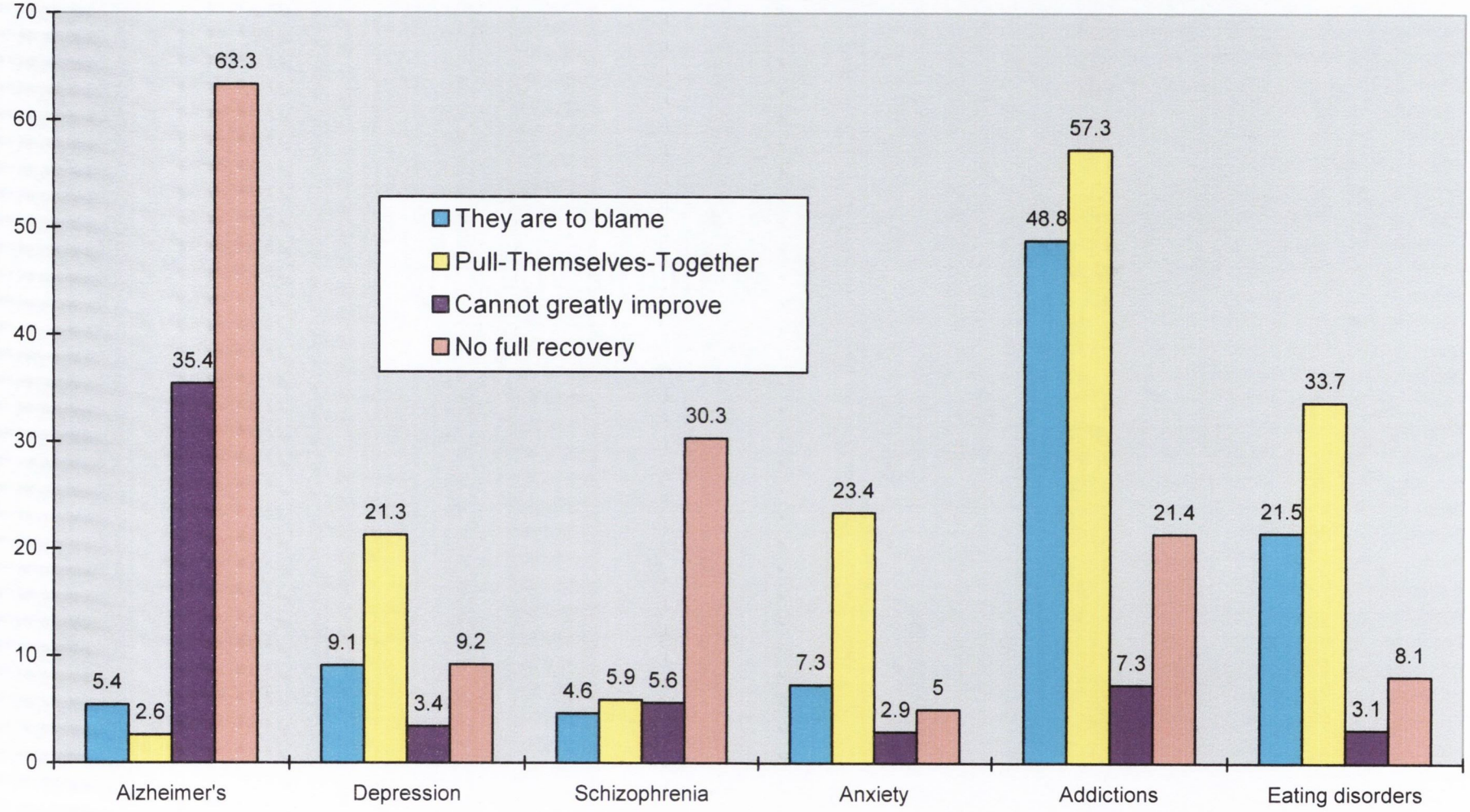


Figure 5.5: *Psychological distance and risk perceptions about six mental disorder: percentages. Base: participants aware of each disorder.*

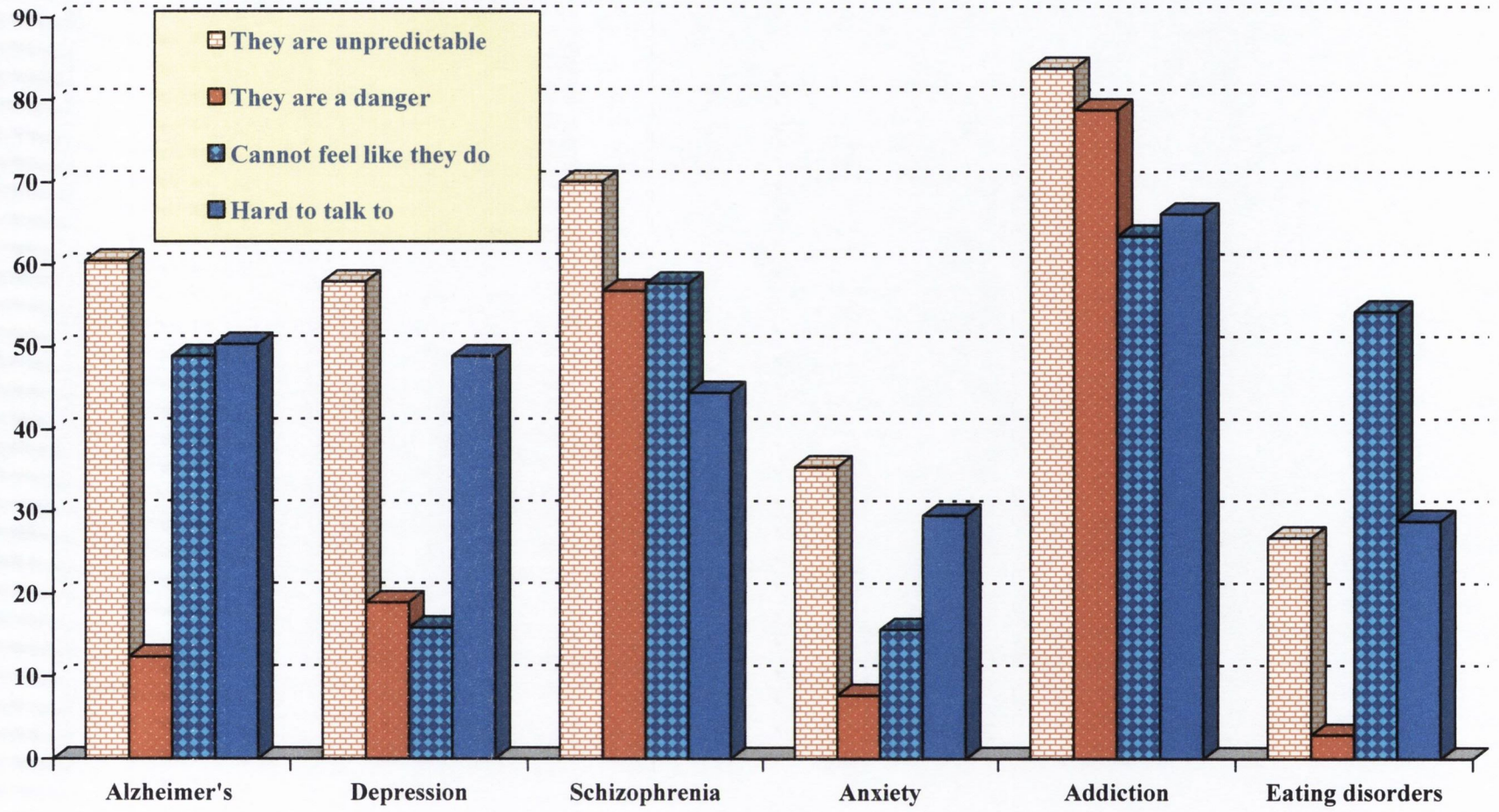


Table 5.1: Binary logistic regression of demographic variables and **Awareness** of six disorders:

Odds ratios (OR) corrected for ***other*** three variables: age, gender, marital status and social class							
		Alzheimer's	Depression	Schizophrenia	Anxiety	Alcohol / drug use	Eating disorders
Age	15-24	1.0	1.0	1.0	1.0	1.0	1.0
	25-34	2.8 ** 1.68-4.68	NS	1.54 * 1.03-2.92	NS	NS	NS
	35-49	3.89 ** 2.2-6.89	NS	1.76 * 1.16-2.66	1.5 * 1.0-2.32	NS	NS
	50-64	3.97 ** 2.13-7.41	NS	1.79 * 1.14-2.79	NS	NS	NS
	Over 65	1.99 * 1.25-3.15	NS	0.59 * 0.42-0.84	NS	0.46 * 0.25-0.86	0.29 * 0.19-0.44
Gender females		1.57 * 1.13-2.17	1.84 * 1.22-2.78	1.35 * 1.06-1.73	1.96 ** 1.51-2.54	NS	2.09 ** 1.56-2.80
Marital status married		2.04 ** 1.34-3.13	2.49 ** 1.49-4.15	1.71 ** 1.28-2.28	1.84 ** 1.36-2.49	1.71 * 1.04-2.81	2.25 ** 1.62-3.12
Social class ABC1		2.68 ** 1.79-4.0	NS: p=0.053	2.67 ** 1.97-3.61	2.23 ** 1.65-3.01	2.09 * 1.23-3.56	2.36 ** 1.66-3.35
Odds ratios (OR) corrected for four variables: age, gender, marital status and social class							
Country: NI		1.77 ** 1.25-2.49	2.75 ** 1.71-4.44	1.83 ** 1.4-2.4	2.32 ** 1.75-3.07	3.13 ** 1.84-5.32	2.20 ** 1.61-3.02
Pop density: NI urban		2.06 * 1.1-3.85	NS	1.98 * 1.25-3.14	1.66 * 1.00-2.74	NS	NS
Pop density: RoI urban		2.37 ** 1.57-3.56	5.09 ** 2.94-8.83	2.82 ** 1.6-3.52	2.87 ** 2.09-3.95	13.2 ** 5.95-29.3	3.52 ** 2.43-5.09

* denotes Significance $p<0.05$; ** denotes Significance $p<0.001$

Table 5.2: Binary logistic regression of demographic variables and **Personal Contact** of six disorders:

Odds ratios (OR) corrected for other three variables: age, gender, marital status and social class							
		Alzheimer's	Depression	Schizophrenia	Anxiety	Alcohol / drug use	Eating disorders
Age	15-24	1.0	1.0	1.0	1.0	1.0	1.0
	25-34	NS	1.62 * 1.19-2.19	2.0 * 1.20-3.23	1.86 * 1.26-2.75	NS	NS
	35-49	1.99 ** 1.44-2.76	1.91 ** 1.42-2.57	1.91 * 1.19-3.08	1.87 * 1.27-2.76	NS	NS
	50-64	3.29 ** 2.37-4.59	1.93 ** 1.41-2.64	2.32 * 1.42-3.77	NS	NS	NS
	Over 65	3.59 ** 2.61-4.96	1.55 * 1.14-2.12	1.98 * 1.21-3.23	NS	NS	NS
Gender females		1.29 * 1.07-1.54	1.45 ** 1.22-1.72	NS	NS	NS	1.83 ** 1.45-2.31
Marital status married		NS	NS	NS	NS	NS	NS
Social class ABC1		1.49 ** 1.24-1.79	1.44 ** 1.21-1.72	1.41 * 1.09-1.82	1.55 ** 1.25-1.93	NS	1.69 ** 1.35-2.13
Odds ratios (OR) corrected for four variables: age, gender, marital status and social class							
Country: NI		1.29 * 1.08-1.55	1.29 * 1.09-1.54	1.64 ** 1.27-2.12	1.84 ** 1.47-2.28	NS	1.84 ** 1.46-2.31
Pop density: NI urban		0.66 * 0.51-0.85	0.72 * 0.56-0.92	NS	NS	NS	NS
Pop density: RoI urban		0.66 * 0.51-0.86	0.73 * 0.57-0.93	NS	NS	NS	NS

* denotes Significance $p<0.05$; ** denotes Significance $p<0.001$

Table 5.3: Binary logistic regression of demographic variables and **Knowledge** excluding contact of six disorders:

Odds ratios (OR) corrected for other three variables: age, gender, marital status and social class							
		Alzheimer's	Depression	Schizophrenia	Anxiety	Alcohol / drug use	Eating disorders
Age	15-24	1.0	1.0	1.0	1.0	1.0	1.0
	25-34	NS	NS	NS	1.70 * 1.2-2.42	NS	0.68 * 0.49-0.95
	35-49	NS	NS	NS	1.71 * 1.2-2.43	NS	0.64 * 0.46-0.89
	50-64	NS	NS	NS	1.75 * 1.21-2.52	0.7 * 0.49-0.98	0.49 ** 0.35-0.71
	Over 65	NS	NS	NS	1.98 ** 1.38-2.84	0.45 ** 0.32-0.64	0.35 ** 0.24-0.51
Gender females		NS	1.64 ** 1.28-2.11	1.42 * 1.14-1.78	1.47 ** 1.2-1.8	NS	1.85 ** 1.86 1.5-2.25
Marital status married		1.41 * 1.09-1.83	1.63 ** 1.32-1.99	NS	NS	NS	NS
Social class ABC1		1.67 ** 1.35-2.08	1.56 ** 1.26-1.92	1.7 ** 1.37-2.12	1.61 ** 1.31-1.97	1.72 ** 1.41-2.09	1.78 ** 1.46-2.18
Odds ratios (OR) corrected for four variables: age, gender, marital status and social class							
Country: NI		NS	NS	NS	NS	1.23 * 1.01-1.49	NS
Pop density: NI urban		NS	NS	NS	NS	NS	NS
Pop density: RoI urban		NS	NS	1.41 * 1.03-1.95	NS	1.59 ** 1.19-2.13	1.52 * 1.14-2.04

* denotes Significance $p<0.05$; ** denotes Significance $p<0.001$

Table 5.4: Binary logistic regression of demographics and **hard to talk to** beliefs about people with six disorders: Base aware of disorder.

Odds ratios (OR) corrected for other three variables: age, gender, marital status and social class							
		Alzheimer's	Depression	Schizophrenia	Anxiety	Alcohol / drug use	Eating disorders
Age	15-24	1.0	1.0	1.0	1.0	1.0	1.0
	25-34	0.49 ** 0.37-0.66	NS	NS	NS	NS	NS
	35-49	0.67 * 0.51-0.89	NS	NS	NS	NS	1.62 * 1.16-2.27
	50-64	NS	NS	NS	NS	NS	1.57 * 1.14-2.19
	Over 65	NS	NS	NS	NS	NS	NS
Gender females		NS	1.19 * 1.01-1.4	0.84 * 0.71-0.99	NS	NS	NS
Marital status married		NS	NS	NS	0.8 * 0.64-0.99	NS	NS
Social class ABC1		NS	NS	0.8 * 0.68-0.95	NS	NS	NS
Odds ratios (OR) corrected for four variables: age, gender, marital status and social class							
Country: NI		NS	NS	0.77 * 0.65-0.92	NS	0.84 * 0.71-1.0	NS
Pop density: NI urban		0.65 ** 0.51-0.84	0.59 ** 0.46-0.75	NS	NS	0.54 ** 0.42-0.69	0.66 * 0.5-0.86
Pop density: RoI urban		0.76 * 0.6-0.96	1.39 * 1.1-1.75	NS	NS	NS	NS
Contact		0.46 ** 0.38-0.56	0.65 ** 0.55-0.78	0.58 ** 0.45-0.75	NS	0.55 * 0.46-0.68	0.69 * 0.55-0.88

* denotes Significance $p<0.05$; ** denotes Significance $p<0.001$

Table 5.5: Spearman's correlations (rho, r) between attitude questions about six mental disorders: Base aware of each condition.

2 Risk questions:	Alzheimer's	Depression	Schizophrenia	Anxiety	Alcohol / drugs	Eating disorders
They are a danger to others + They are unpredictable	0.209 **	0.301 **	0.591 **	0.286 **	0.59 **	0.116 **

Social distance:	PTT Eating disorders	Blame Eating disorders	Blame Addicts	PTT Depression	PTT Anxiety
Hard to talk to them	0.041 *	NS	0.183 **	0.112 **	0.144 **
Feel different to us	0.135 **	0.082 **	0.177 **	-0.06 *	-0.059 *

Social distance:	Danger Addictions	Unpredictable Addictions	Danger Schizophrenia	Unpredictable Schizophrenia
Hard to talk to them	0.25 **	0.418 **	0.375 **	0.467 **
Feel different to us	0.262 **	0.254 **	0.317 **	0.396 **

Social distance:	Danger Depression	Unpredictable Depression	Danger Anxiety	Unpredictable Anxiety
Hard to talk to them	0.219 **	0.388 *	0.238 **	0.396 **
Feel different to us	NS	-0.061 *	NS	NS

PTT: pull-yourself-together attitudes. * denotes Significance $p<0.05$; ** denotes Significance $p<0.001$

Table 5.6: The associations of Knowledge (excluding contact) and Contact on four attitudes: Percentages. Base: aware of disorder

Question		Alzheimer's	Depression	Schizophrenia	Anxiety	Alcohol /drugs	Eating disorders
We can not feel like they do	**Good** knowledge	**55.9** **	**14.6** *	**66.1** **	**15.7 NS**	**65.8** *	**57.2 NS**
	Poor knowledge	42.5	19.7	55.1	17.9	60.7	53.9
	Contact	**54.7** **	**11.7** **	**59.9 NS**	**8.3** **	**66.0 NS**	**51.9 NS**
	No contact	46.5	17.8	57.7	17.2	62.6	54.9
They are hard to talk to	**Good** knowledge	**61.0** **	**52.5** **	**56.9** **	**33.4** *	**72.0** **	**37.6** **
	Poor knowledge	37.3	41	38.6	27.3	57.1	22.9
	Contact	**65.3** **	**56.2** **	**57.4** **	**31.1 NS**	**75.3** **	**36.4** **
	No contact	44.3	45.2	42.7	29.3	62.8	27.4
They are unpred-ictable	**Good** knowledge	**70.2** **	**65.9** **	**85.9** **	**45.0** **	**90.0** **	**36.0** **
	Poor knowledge	48.7	47.3	64	30.7	75.3	21.6
	Contact	**73.7** **	**66.5** **	**78.7** **	**36.5 NS**	**92** **	**31.8** *
	No contact	55.1	54.1	68.9	35.3	80.9	26.0
They are a danger to others	**Good** knowledge	**17.8** **	**20.7 NS**	**71.1** **	**8.7 NS**	**85.4** **	**4.6 NS**
	Poor knowledge	10.4	18.4	52.7	7.2	71.8	2.5
	Contact	**12.1 NS**	**18.6 NS**	**58.1 NS**	**7.8 NS**	**83.8** **	**1.9 NS**
	No contact	12.6	19.2	56.8	7.7	77.0	3.1

* $p<0.01$ **$p<0.001$ and NS = no significance

Table 5.7: *Total Social Distance, TSD, mean scores (minimum 3, maximum 15) with standard deviation in brackets.*

	Alzheimer's	Depression	Schizophrenia	Anxiety	Alcohol /drugs	Eating disorders
Mean TSD (st dev) Aware of disorder	10.68 (2.02) n=1,733	9.24 (1.77) n=2,035	11.44 (1.95) n=1,406	8.27 (1.99) n=1,737	11.74 (1.94) n=2,055	9.06 (2.04) n=1,611
Independent paired t test of TSD with:	t value, significance	t value, significance	t value, significance	t value, significance	t value, significance	t value, significance
Contact	t=6.0, **	t=0.24, NS	t=2.31, *	t=2.51, NS	t=3.18, *	t=1.04, NS
Knowledge	t=4.84, **	t=0.26, NS	t=2.31, *	t=2.43, NS	t=0.7, NS	t=1.78, NS
Danger belief	t=4.07, **	t=11.38, **	t=13.37, **	t=9.9, **	t=18.84, **	t=4.11, **
Exclusion of contact:						
Knowledge	t=2.84, *	t=0.69, NS	t=4.26, **	t=0.89, NS	t=0.31, NS	t=1.31, NS
Danger belief	t=4.25, **	t=9.86, **	t=13.35, **	t=8.96, **	t=19.03, **	t=4.24, **

* $p<0.01$ **$p<0.001$ and NS = no significance

Table 5.8 Summary of key findings about the six mental disorders from Study Two

	Awareness	Contact	Knowledge	Pessimism about treatment	Blame	Social distance	Unpredictability	Perceived danger
Alzheimer's	Good	Good	Good	Yes	No	High	Moderate	No
Depression	Good	Good	Good	No	Some	Low	Moderate	No
Schizophrenia	Poor	Poor	Poor	Some	No	High	Moderate	High
Anxiety	Poor	Poor	Fair	No	Some	Low	Low	No
Addictions	Good	Good	Good	No	Strong	Very high	High	High
Eating disorders	Fair	Poor	Fair	No	Strong	High	Low	No

Table 5.9 Summary of four demographic and two location influences (corrected for other demographics)

	Low Awareness	Low Contact	Poor Knowledge	High PTT beliefs	High TSD	High danger
Age: younger	AnxietyDepression	AnxietyDepression	NS	AnxietyDepression	NS	NS
	Schizophrenia	Schizophrenia	NS	NS	NS	NS
	NS	NS	NS	NS	NS	NS
Age: older people	AnxietyDepression	AnxietyDepression	NS	NS	NS	NS
	Schizophrenia	Schizophrenia	NS	NS	Schizophrenia	NS
	Addictions	Addictions	Addictions	NS	Addictions	NS
Male gender	AnxietyDepression	AnxietyDepression	AnxietyDepression	AnxietyDepression	NS	NS
	Schizophrenia	Schizophrenia	Schizophrenia	NS	NS	NS
	NS	NS	NS	NS	Reverse: see text	NS
Lower Socioeconomic group	NS	AnxietyDepression	AnxietyDepression	NS	NS	NS
	Schizophrenia	Schizophrenia	Schizophrenia	NS	NS	Schizophrenia
	Addictions	Addictions	Addictions	Addictions	NS	NS
Single people	AnxietyDepression	NS	AnxietyDepression	NS	NS	NS
	Schizophrenia	NS	NS	NS	NS	NS
	NS	NS	NS	NS	NS	NS
Rural	AnxietyDepression	NS	Reverse: see text	AnxietyDepression	NS	NS
	Schizophrenia	NS	Schizophrenia	NS	Schizophrenia	NS
	Addictions	NS	Addictions	NS	Addictions	NS
RoI	AnxietyDepression	AnxietyDepression	NS	NS	NS	AnxietyDepression
	Schizophrenia	Schizophrenia	Schizophrenia	NS	NS	Reverse: see text
	Addictions	NS	Addictions	NS	NS	Addictions

TSD Total Social Distance; NS No Significant association; "Reverse: see text" indicates associations opposite to those expected.

Chapter Six: Results and Discussion of Study Three

Knowledge and Attitudes towards Electroconvulsive Treatment (ECT) among health care professionals and students of medicine and nursing

6.1 Aims of Study Three and Hypotheses 6 and 7

6.1.1 (1) To recruit health professionals and students to administer a self-rating questionnaire that measures their knowledge and attitudes towards ECT.

(2) To measure knowledge and attitudes among professional groups, with particular reference to personal experience of the procedure ("contact").

6.1.2 Hypothesis 3: Levels of ECT knowledge promote more positive attitudes.

Hypothesis 5: Contact with ECT predicts better knowledge and more positive attitudes

6.1.3 The single page questionnaire had six statements, each with a 5-point Likert scale: Section 3.3. For the mortality question, don't know was indicated by failing to indicate any of the four mortality rates, and respondents were divided into two groups: correct (mortality between 1 in 10,000 and 100,000 ECT applications) and incorrect (mortality more than 1 in 1,000 and 1 in 100 treatments). For the six questions, there are three possible responses: incorrect, don't know or correct. Univariate analyses, which included polycotonous regression, were applied to all data, as set out in Section 3.3.7. The exact proportions of groups and subgroups will be set out for all statements, but the main interest is in differences between medical and nursing respondents, and the associations between contact and knowledge with these answers. Contact is defined as a student who has completed psychiatry, a professional who has applied ECT (all psychiatrists in this study), or has assisted at ECT (anaesthetists, theatre nurses) in the last year.

6.2 Description of respondents

Of 593 questionnaires distributed, all were returned and included for the statistical analysis on SPSS (SPSS Inc., 2002). Respondents were asked to mark and return

the questionnaire even if they did not answer every question. Figure 6.1 classifies respondents by occupation and location. 413 were from Dublin, and 180 from Cork, 383 belonged to the medical profession (as medical students or qualified doctors), with 210 nursing professionals (student and qualified nurses). The majority, 416 (70.2%), were undergraduate students (of medicine and nursing). Of these, 182 had not completed any formal psychiatric training apart from some psychiatric lectures. The students comprised 134 nursing and 282 medical students. 46 nursing students (34.3%) had completed psychiatric placement, but a higher proportion of medical students (66.7%, n= 188) had completed their two month rotation in psychiatry. All 37 psychiatrists were based in Dublin, but there were 64 anaesthetists (consultants and specialist registrars) and 76 nurses from both cities (Figure 6.1). Of 37 trainee psychiatrists, 24 were attending lectures for part one of the MRCPsych (Membership of the Royal College of Psychiatrists) diploma, and 13 had passed this exam, and were attending more advanced lectures to complete part two MRCPsych. We did not differentiate within this group for analyses, nor did we separate consultant anaesthetists from senior registrar colleagues. Of 76 nurses, 34 were psychiatric nurses working in Dublin and Cork, and 42 were theatre nurses from both cities.

6.3 Knowledge about ECT mortality

6.3.1 Six people (1% of respondents) believed that 3 or more patients died per 100 ECT treatments. All six had a nursing background, of which five were students. Three out of these five students had completed their psychiatric attachment and five out of six were based in Cork. All six endorsed four or more subsequent questions negatively. 30 (5.1%) did not know or did not answer the question about the death rate per ECT treatment. These were 23 students (11 medical and 12 nursing) and 7 professionals (2 anaesthetists and 5 nurses, four of whom were psychiatric nurses). 121 respondents (20.4%) overestimated the mortality rate, and this number includes the 6 respondents holding ECT to have a 3% mortality (Table 6.1). 35 were from Cork (19.4% of Cork respondents) with 86 (20.8%) from Dublin. Over one third

(35.3%) of psychiatric nurses believe that mortality is 3 in 10,000 or greater, and this compares with the 21.4% of theatre nurses holding the same belief. Almost a quarter of trainee psychiatrists (24.3%) overestimated the mortality rate. There were significant differences between psychiatrists and anaesthetists, but none between anaesthetists had assisted at ECT and those who had not. Answers to mortality were calculated excluding six respondents who deemed ECT 3% fatal, and significance remained: $\chi 2= 14.3$, df=2, $p<0.001$ with linear-by-linear $\chi 2= 10.3$, df=1, $p<0.001$.

6.4 ECT prescription and patient choice

6.4.1 A second statement concerned the perception of coercive shock treatment: "ECT is usually given to patients against their will". 98 (16.5%) did not know or gave no answer (Table 6.1). A higher proportion (19.8%) of professionals than students (15.1%) could not answer. This comprised a third of psychiatric nurses, one quarter of theatre nurses and one fifth of anaesthetists. 54 (55.1%) of this group also failed to give an opinion about ECT efficacy in relation to ADs: $\chi 2=48.3$, df1; $p<0.001$. The groups with the highest proportion of correct answers in descending order were psychiatric trainees, medical students, anaesthetists, nursing students, theatre nurses and (lowest correct scores) psychiatric nurses. There were no significant differences between nurses based on speciality, though a trend showed more correct answers from theatre nurses. Negative beliefs about coercion were significantly higher in nursing than medical students, nurses more than doctors, with nursing versus medical group significantly associated with the incorrect answer (Table 6.1). For both student groups, completion of rotation was significantly associated with the correct answer. All but one trainee psychiatrist answered correctly, exceeding anaesthetists in the proportion of correct answers.

6.4.2 A third statement read: "the majority of patients who have ECT will refuse to have the treatment again". 175 (29.5%) did not know or did not answer this question, higher than for the previous two questions: 52.9% of psychiatric nurses, 35.7% of theatre nurses and 17.2% of anaesthetists. Similar proportions of anaesthetists

indicated don't know, irrespective of recent ECT contact. Most of the don't knows were students, and though similar in numbers, the proportion of nursing students was significantly higher than medical, 50.7% and 21.6% respectively (Table 6.1). For nursing students, non completion was associated with no answer ($\chi 2=8.4$, df=2; p=0.015) as it was for medical students ($\chi 2=22.9$, df=2; p<0.001). As with the other consent question, not answering this question was also associated with failure to answer about AD efficacy: $\chi 2=48.4$, df=2; p<0.001.

6.4.3 Most respondents knew that it is untrue to state that most patients refuse more treatment: 352 (59.4%) and 66 (11.1%) believed the opposite. For students, completion was significantly associated with the correct answer (Table 6.1). The correct answer groups in descending order were psychiatric trainees, anaesthetists, medical students, nursing students, psychiatric nurses and (lowest correct scores) theatre nurses. All of these differences reached significance with the exception that there were no internal differences between doctors. Membership of the medical group had the strongest associations with being correct: (Table 6.1).

6.5 ECT side effects: brain damage

The fourth information question read "if it is used excessively, ECT can cause permanent brain damage": Table 6.1. One third (n=201, 33.9%) did not know, the highest proportion of the four knowledge questions. While a similar proportion of nurses and nursing students didn't know, 52.9% of all psychiatric nurses comprised this category. The highest numbers of correct answers were (in descending order) psychiatric trainees, anaesthetists who assisted, anaesthetists who did not, medical students, theatre nurses, nursing students and psychiatric nurses. Perceptions about brain damage were significantly higher in nursing than medical students, nurses more than doctors, with nursing versus medical group significantly associated with the incorrect answer (Table 6.1). There was a significant association between correct answers and contact in medical students, but there were no education effects on the nursing student group. Only 9% of the total nursing group answered this question

correctly. Psychiatric trainees have the highest correct scores here, 97.3%, without significant differences between them and anaesthetists. Unique to this question assisting anaesthetists knew more than anaesthetists who had not assisted at ECT.

6.6 Subjective beliefs about efficacy and prescription

6.6.1 The fifth question concerned the perceived efficacy of ECT: "ECT is not as effective as antidepressant (AD) medication". A large number of respondents, 177 (29.8%) did not answer or indicated don't know to this question, similar to the third statement about consent to future treatment (Section 6.4.2). A similar proportion of professionals and students (28.2% and 30.5% respectively), and people from Dublin (28.6%) and Cork (32.8%), comprised this group. A clear majority of nurses failed to answer this question, 55.3%, with a higher proportion of nursing students (59.7% of total). One fifth of medical students who had not completed their psychiatric placement could not answer, nor could 12.5% of anaesthetists (Table 6.1).

6.6.2 Over 70% of this sample did answer the question, with 55.1% (n = 327) of all respondents giving the correct response (ECT is equal to or more effective than ADs), and 15% (n = 89) answering incorrectly. For the overall group, and for each sub-group, their location (Dublin or Cork) was not significant. For medical but not nursing students, completion of psychiatric placement significantly determined the correct answer. When the group are divided into contact and no contact, this reaches significance with linear trend effects (Table 6.1).

6.6.3 The sixth question related to the likelihood that respondents would prescribe, or encourage prescription of, ECT for the subgroup of patients who benefit from its treatment. It asked respondents "in severe depression, ECT should be considered a last resort". Only seventy respondents (11.8%) did not answer, with a higher proportion of nursing (18.1%) than medical colleagues (8.4%). More were incorrect than correct: 50.4% and 37.8% respectively. Unique of all seven questions, there were significant differences between medical students who had finished their psychiatry and doctors who had contact with ECT. High numbers of medical students

who had completed, 43.5% correct, should be compared to low completed nursing students, 13%, and higher proportion of doctors, 75.2% (Table 6.1). As with the previous attitude question, there was a significant difference between psychiatrists and anaesthetists, but this was not linear (Table 6.1).

6.6.4 For each of the first five questions, the value "1" was assigned to the correct answer and "0" for incorrect, don't know or no answer, to calculate a total knowledge score. Respondents scoring 0 or 1 were 9.9% and 42.8%, and scoring 4 or 5, 57.1% and 10.9%, for medical and nursing groups respectively. The distribution of knowledge scores was non parametric. There were direct relationships between low knowledge and negative attitude: $Z=10.52$; $p<0.001$. Among medics, a Mann-Whitney $Z=12.41$; $p<0.001$, and, for students, exposure to ECT was directly related to better knowledge: $Z=9.21$; $p<0.001$. Despite no contact with ECT by theatre nurses in this study, there were no significant differences on knowledge scores compared to psychiatric nurses. Within the nursing group, there are no associations between better knowledge and attitude to prescription: $Z=0.15$; $p=0.88$.

6.7 Logistic regression and summary of main findings

6.7.1 To test the relative contributions of four independent dichotomous variables, student – professional, contact – no contact, Dublin – Cork, and medical – nursing group, binary logistic regression was carried out for six questions. Consistent with the linear-by-linear analysis, for each question all three possible answers were included in binary regression: correct as the first variable, and don't know plus incorrect answers as the second. Of the four independent variables, membership of the medical group and contact had independent associations with the correct answer in six questions: (Table 6.2). In all cases, being medical and having contact predicted more knowledge and more positive attitudes. Although Dublin location reached significance for the future consent question, this unexpected finding may have been a false positive result from multiple analyses. Student status was significant only in one question, "against their will", where they were more likely than qualified professionals

to be correct about coercive ECT. For the other five statements, the potent determinants are contact and medical group: (Table 6.2).

6.7.2 In the light of the strong influence of professional status on all parameters, binary logistic regression of student status and contact was carried out separating the nursing from the medical group. For the nursing group, the only significant differences for students related to the consent questions, where students were more likely to be correct than nurses: OR=0.21 (0.09-0.49), p<0.001 and OR=0.26 (0.12-0.58), p<0.001 for against their will and future refusal respectively. Contact had only one significant association in the nursing group – about future consent: OR=0.26 (0.12-0.54), p<0.001. In the medical group, there were two questions where student status independently predicted differences. Students were less likely to be correct about brain damage and ECT as last resort: OR=1.73 (1.06-2.82), p<0.001 and OR=2.62 (1.53-4.47), p<0.001 respectively. In contrast to nursing students, contact with ECT by medical students always predicted better knowledge and attitudes.

6.7.3 The relationships between questions were tested by calculating Spearman's correlation coefficient, rho, for each combination. Analysis was carried out as both 3-way answers (incorrect, don't know and correct) and 2- way (incorrect combined with don't know responses with correct as the second category). All correlations reached significance with the single exception of a 2- way correlation between mortality and future prescription. As expected, the highest correlations were between two pairs of similar questions, the two about consent (Section 6.4) and those about efficacy and prescription (Section 6.6), with 2-way correlations of 0.427, p<0.001 and 0.423, p<0.001 respectively. Good knowledge of the two consent questions had consistent correlations with the last resort question: rho 0.33 and o.37, p<0.01 respectively.

6.7.4 Excluding the don't knows to facilitate binary logistic regression, being a nurse or nursing student had an odds ratio (OR) of 5.46 (3.25 – 9.18), Wald=40.9, df=1; p<0.001 of being incorrect about efficacy of ECT. When this is corrected for student status, completion and location, OR = 5.06 (2.92 – 8.77), Wald=33.4, df=1;

$p<0.001$. For the "last resort" question, there were strong divisions along professional lines with significant differences between nursing and medical students, nurses and doctors, and nursing and medical groups. This question had the poorest answers from medical students (Table 6.1), but the majority of nursing students and nurses, 70.1% and 68.4% respectively, perceive ECT as a last resort. There were no significant differences between these two groups on this question. Excluding the don't knows to facilitate binary logistic regression, being a nurse or nursing student had an odds ratio (OR) of 7.26 (4.55 – 11.59), Wald=69.1, df=1; $p<0.001$ of being incorrect about prescription of ECT. When this is corrected for student status, completion and location, OR = 8.5 (5.03 – 14.37), Wald=63.9, df=1; $p<0.001$.

6.8 Discussion of Study Three

6.8.1 High proportions of don't know responses were recorded (Table 6.1). A don't know answer in one parameter predicted don't knows in others (Sections 6.4.1 and 6.4.2). Although Study Three found poor **knowledge** and negative attitudes in only a minority if respondents, there are some areas of concern, especially among nurses and nursing students: 24.3% of psychiatric trainees overestimate mortality. Nursing respondents are twice as likely to overestimate ECT mortality, even correcting for student status, completion and location. The mortality question should be seen as the most factual / least contentious aspect of ECT knowledge, and its association with independent variables should be seen in the context that only 7% of respondents overestimated it (Table 6.1). However, nursing respondents are four times more likely to wrong about consent, five times more likely to underestimate its efficacy, and eight times more likely to see it as a last resort. A medical background also predicts information about coercion, and in this instance, qualified nurses are less likely to be correct than nursing students. Study Three replicates previous findings (Table 2.4) that identified proportions of professionals and students who are strongly antipathetic to ECT: in one study, 25% of medical students (Andrade and Rao, 1996). Janicak et al (1985) reported negative ECT views among psychologists and social workers,

replicating Kalayam and Steinhart (1981) where these views were even more negative than the general public's. Study Three's findings contradict Gass (1998) who reported higher knowledge among more experienced nurses. Low knowledge and negative attitudes characterise the nursing group: (Section 6.4). Lutchman et al (2001) concluded that discipline was the strongest predictor of knowledge and attitudes to ECT. In Study Three, membership of the nursing fraternity always increases poor knowledge and negative attitudes – more than any other parameter.

6.8.2 There were weak correlations between information and **attitudes**: (Section 6.7.3), and this reflects the lack of association between knowledge and attitudes among the nursing group. Brain damage beliefs are very strong in the total nursing group: only 9% answered this correctly, and nurses are six times more likely to be wrong about this (Section 6.4). Nor were there differences between nursing students and nurses in their attitudes to efficacy and prescription. These two attitudes were not influenced by completion of training in nursing students. Although the design of Study Three only permits the calculation of associations, not causes, either better knowledge about consent drives positive attitudes to ECT, or positive attitudes encourage respondents to believe that patients' consent is the rule not the exception. Some studies have also cast doubt on the information → attitudes formula: Jaffe et al (1990) found no relationships between psychiatric trainees' knowledge and previous teaching and experience. Clothier et al (2001) reported predominantly negative attitudes among junior medical students from the southern US state of Arkansas, but with the key finding that those who rated their knowledge as very good were more likely to be biased against ECT. Study Three shows that the benefits of knowledge were confined to medical students. **Hypothesis 3**, as it relates to ECT, is not proven.

6.8.3 Students with **contact** had significantly less don't know responses that those who had not (Section 6.4.2). Linear regression confirms contact as a significant determinant of positive answers in six parameters, with the single exception of mortality (Table 6.2). This replicates one previous intervention study (Benbow, 1990)

and confirms the benefits of training of Szuba et al (1992). The former intervention study show significant and consistent improvements in don't know scores in its medical student population (Benbow, 1990). Contact does not have the same effect on nursing respondents: Section 6.7.3. It also seems the case that where knowledge and attitudes are already good, contact adds little additional benefit: for anaesthetists, only brain damage knowledge improved in the contact group (Table 6.1). **Hypothesis 5**, as it relates to contact with ECT, is not proven for anaesthetists (Section 6.4.1), nurses (Section 6.7.2) or nursing students (Section 6.5).

6.9 Limitations of Study Three

6.9.1 The sample questioned in Study Three (health professionals and students) represents an "opportunity sample" (Olmstead and Durham, 1976) – a population readily available but perhaps unreflective of all nursing and medical groups, and perhaps unrepresentative of the general public's views. In the interests of high compliance, we wished to assure anonymity: no details of age, gender or work experience were requested. The 100% response rate reflects 100% compliance, where respondents were asked to fill a questionnaire before a lecture or presentation, but this also led to high numbers of don't know responses (Tables 6.1 to 6.7). As a rule, the proportions of don't know answers were always higher in the nursing than medical groups. There are many explanations for this other than low knowledge and antipathy among nurses: medical training has more "multiple choice question" exams with a yes / no format. Professional mindsets may also play a role, for example medical certainties or nurses' ability to identify and accommodate ambiguity. A doctor (PB) wrote the questionnaire, but a different format, perhaps vignettes, would have matched problem based learning methods of nursing colleagues better. It must also be noted that doctors legally prescribe ECT, but nurses do not: perhaps these statutory roles impact on knowledge and attitudes. None of the theatre nurses sampled had assisted at ECT (Figure 6.1), and this would

be expected as anaesthetists alone assist in ECT in designated units in each centre. Sampling bias must be considered with specific reference to:

- Only people who attended their psychiatry lectures or anaesthetic seminars were approached for the study. Responses from this group could reflect either broad pro-psychiatry views or strong contrary opinions
- About two thirds of medical students had completed their psychiatric rotation, compared to one third of nursing students (Section 6.2): this reflects the access two researchers (PB and BC), both tutors, had to fourth and final year medical students. While completion was always considered in regression (Section 6.8), this imbalance reflects disproportionately more final year medical students and more junior nursing students in the study group.
- This was a questionnaire study, and each of three researchers invited people to fill a questionnaire without comment. However, all Cork nursing students were recruited by one researcher (PB) who was about to give them a formal lecture on ECT. Some respondents may therefore have given ideal responses, and these could explain the location differences reported.
- The wide variation in ECT prescription by senior psychiatrists was set out in Section 2.8, but Study Three only examined the attitudes of psychiatric trainees, and these were based in only one of the two centres (Dublin). Their opinions were intended as a standard against which students and other professionals could be measured, but Study Three may have simplified the issues in neglecting to question consultant psychiatrists in both centres.
- Conclusions about the effect of recent contact with ECT applications are limited given the study's failure to enlist any theatre nurses who had assisted at the procedure (Figure 6.1). The fact that less than only half of theatre nurses were correct about coercion (Table 6.1) should be seen in the context that no theatre nurses had seen ECT in the previous year.

6.9.2 Study Three did not have a qualitative component where respondents' views were discussed in depth, or where answers were checked to clarify meanings. Four respondents wrote "it depends", "don't understand question" or similar, and two wrote that "patients do not understand ECT". Finally, there was no follow up questionnaire nor did we measure intended or actual or behaviour.

6.10 Implications for service users

One of the many paradoxes about ECT is that the subgroups who actually receive the treatment will surprise its opponents: (Section 2.8.2). Freeman and Cheshire (1986) reviewed 10 studies that examined lay attitudes to ECT, including service users': themes of these studies (pain, consent, punishment, side effects and the role of the media) were incorporated into Study Three's questions. In three of the studies they reviewed, people who had had ECT were compared to ECT naïve subjects or to lay opinion: all three confirmed the former group was more positive about the procedure (Freeman and Cheshire, 1986). Talk of prejudice among the public must be seen in the context of the professional antipathy reported in Study Three. The issue of informed consent was also raised in Section 2.8, and Study Three's negative findings about poor nursing knowledge and negative nursing attitudes toward ECT have particular relevance here. If the growing demand by UK service users for advanced directives that they will *never* have ECT no matter what befalls them (Rose et al, 2002) reflects public prejudice against the procedure, and that prejudice is shared by many nursing professionals, it is likely that its prescription in the UK will continue to fall (Section 2.8). If, as reported in Study Three, only one psychiatric nurse (2.9%) perceived ECT as more effective than antidepressants, a discussion on ECT between a psychiatric nurse and a patient does not meet the criteria for informed consent. Poor quality factual advice will undermine consent for, or advanced directives about ECT. Negative perceptions of a safe and effective treatment are preventing open discussion of its application in a vulnerable population, where hopelessness is a treatable component of illness.

6.11 Implications for students and health professionals

Janicak et al (1985) and Lutchman et al (2001) concluded that it was professional experience not training which achieved better attitudes. It is perhaps the most pessimistic finding in this thesis that in a relatively simple opinion set (ECT attitudes among health care professionals), there are equivocal findings about the benefits of contact. For medical students, even the contact group continues to view ECT as a last resort compared to doctors. We reported poor knowledge and negative attitudes to ECT among nurses, and in many instances, psychiatric nurses are worse than their theatre-based peers. There were few positive effects of either seniority or contact with the procedure on the nursing group. The clinical implications here are that the professionals who have most contact with psychiatric inpatients (by definition, the subgroup who *may* require ECT) have a prejudice against its use, based on poor information. This has consequences beyond fair access to treatment and questions the efficacy of the interdisciplinary team. It would be easy to blame the limited nursing literature on ECT (Section 2.8), when the onus is on psychiatrists to openly discuss the risks and benefits of ECT with nursing colleagues, and to challenge any negative attitudes. Perhaps a climate of no discussion further hardens nursing attitudes, where it is assumed that a psychiatrist who does not defend ECT, *cannot* defend it. Many of Study Three's findings are also relevant to GPs: they are gatekeepers for psychological morbidity (Goldberg and Huxley, 1994), they see more psychiatric patients than CMHT psychiatrists, and they are frequently consulted for advice about psychiatric treatments by their patients. Though professionals' views of ECT are a frequent topic of research (Table 2.5), no-one has sought or measured GP knowledge and attitudes. GP surgeries are run by the same medical and nursing students questioned in Study Three: where there are prejudices, about people with mental illness or its treatments, these need to be identified and challenged.

Table 6.1: Answers to six statements about ECT with polychotonous univariate analyses

		Medical students	Nursing students	Contact students	No contact students	Doctors	Nurses	Medical group	Nursing group
Six statements	Percentages								
Mortality rates from ECT are between 3 in 10,000 and 3 in 100,000 treatments	Incorrect	18.4	27.6	17.5	26.4	10.9	27.6	16.4	27.6
	Don't know	3.9	9.0	3.0	8.8	2.0	6.6	3.4	8.1
	Correct	77.7	63.4	79.5	64.8	87.1	65.8	80.2	64.3
	significance	*		*		**		**	
"ECT is usually given to patients against their will"	Incorrect	6.7	9.0	3.4	11.0	2.0	28.9	4.7	16.2
	Don't know	9.9	26.1	8.1	24.2	13.9	27.6	11.0	48.1
	Correct	84.4	64.9	88.5	64.8	84.2	43.4	84.3	35.7
	significance	**		**		**		**	
"The majority of patients who have ECT will refuse to have the treatment again"	Incorrect	11.0	9.7	6.8	15.4	1.0	27.6	8.4	16.2
	Don't know	21.6	50.7	19.7	45.6	12.9	43.4	19.3	48.1
	Correct	67.4	39.6	73.5	39.0	86.1	28.9	72.3	35.7
	significance	**		**		**		**	
"If it is used excessively, ECT can cause permanent brain damage"	Incorrect	39.0	49.3	33.3	53.8	24.8	40.8	35.2	46.2
	Don't know	30.1	44.8	32.5	37.9	21.8	44.7	27.9	44.8
	Correct	30.9	6.0	34.2	8.2	53.5	14.5	36.8	9.0
	significance	**		**		**		**	
"ECT is not as effective as antidepressant medication in the treatment of depression"	Incorrect	13.8	16.4	12.4	17.6	7.9	26.3	12.3	20.0
	Don't know	16.7	59.7	17.5	47.3	7.9	55.3	14.4	58.1
	Correct	69.5	23.9	70.1	35.2	84.2	18.4	73.4	21.9
	significance	**		**		**		**	
"In severe depression, ECT should be considered a treatment of last resort"	Incorrect	47.9	70.1	49.6	62.1	17.8	68.4	40.0	69.5
	Don't know	8.9	19.4	4.7	22.0	6.9	15.8	8.4	18.1
	Correct	43.3	10.4	45.7	15.9	75.2	15.8	51.6	12.4
	significance	**		**		**		**	

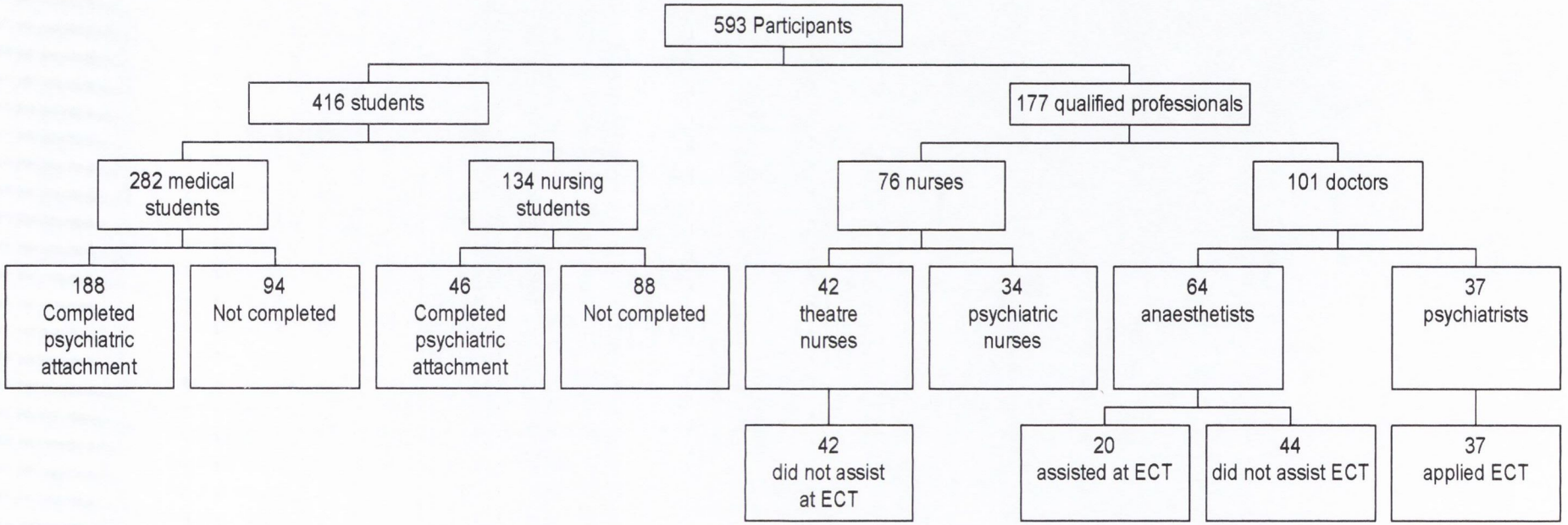
* $p<0.01$; ** $p<0.001$

Table 6.2: Binary logistic regression of correct or not (incorrect plus don't know) based on four groups

Six statements	Variable:	Student status	Contact with ECT	Dublin location	Medical group
Mortality rates from ECT are between 3 in 10,000 and 3 in 100,000 treatments	Odds ratio	1.13	0.65	1.29	0.46
	95% C.I.	0.69-1.85	0.39-0.98	0.39-0.98	0.31-0.69
	significance	NS	*	NS	**
"ECT is usually given to patients against their will"	Odds ratio	0.34	0.33	1.1	0.31
	95% C.I.	0.19-0.57	0.19-0.56	0.71-1.72	0.20-0.46
	significance	**	**	NS	**
"The majority of patients who have ECT will refuse to have the treatment again"	Odds ratio	0.85	0.34	1.91	0.21
	95% C.I.	0.54-1.34	0.22-0.53	1.26-2.89	0.14-0.32
	significance	NS	**	*	**
"If it is used excessively, ECT can cause permanent brain damage"	Odds ratio	1.65	0.23	0.95	0.17
	95% C.I.	1.06-2.58	0.13-0.43	0.61-1.48	0.09-0.29
	significance	p=0.028 NS	**	NS	**
"ECT is not as effective as antidepressant medication in the treatment of depression"	Odds ratio	0.86	0.33	0.97	0.11
	95% C.I.	0.54-1.38	0.20-0.52	0.64-1.48	0.07-0.17
	significance	NS	**	NS	**
"In severe depression, ECT should be considered a treatment of last resort"	Odds ratio	2.03	0.31	0.81	0.12
	95% C.I.	1.29-3.21	0.19-0.51	0.53-1.24	0.07-0.20
	significance	*	**	NS	**

* $p<0.01$; ** $p<0.001$; NS no significance

Figure 6.1: Description of respondents



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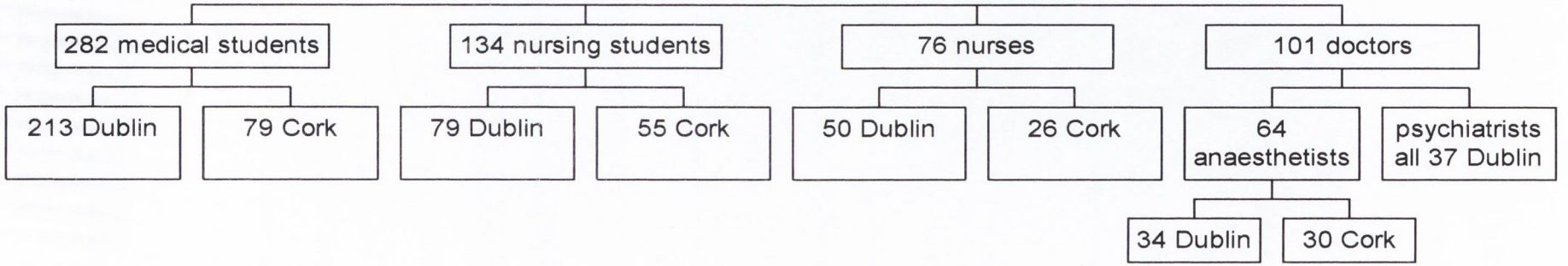

Chapter Seven: Lessons for stigma research

7.1 Expected and unexpected findings

7.1.1 Accepting the studies' limitations, analyses confirmed the validity of current conceptual models of stigma: Section 1.1. Hypothesis 1 is supported by finding associations between stigma, anxiety and alcohol use: Section 4.6. Properly designed, public attitude surveys can build up profiles of disorders (Hypothesis 2) but not the people who endorse negative attitudes towards people who have them: anti-stigma interventions should identify key issues (stereotypes, beliefs, key messages) rather than target groups. Study Two confirms the consensus that negative attitudes among the Irish public are increasing, and fear appears to drive these attitudes (Hypothesis 4). There are many plausible explanations for this increase, of which psychiatric service development is one. Glasson (1996) makes the point that current UK media excesses about mental health should be seen in the context of wider public concerns about how mental health professionals work. She identifies many failures of community care, and cites poor liaison between health and social services, closure of psychiatric hospitals before development of community facilities, and inadequate community support as important considerations (Glasson, 1996). In some areas, the pace of deinstitutionalisation has exceeded resources to rehabilitate and integrate: over two decades, the Massachusetts inpatient population fell from 23,000 to 2,000 (Hinshaw, 2000). It may be that failures of community care in the past two decades (Burns and Priebe, 1999) have led to stereotype conformation (Section 1.5.3), and thereby a hardening of public attitudes toward people with mental illness. Rossler et al (1995) compared two Central European regions, and reported increased rejection of people with mental illness in the region with a stronger community care programme. In disproving the *treatment as cure* argument, or that blame is a major component of societal stigma (Hypothesis 4), Study Two challenges the medical-educational model of stigma reduction.

7.1.2 Negative findings merit discussion, in particular the failure to prove Hypotheses 3 and 5. The contact hypothesis was unproven rather than disproved: Sections 5.7 and 6.7. In defining a population without any mental illness label but with stigma-driven anxieties, Study One helps identify the complexity of "contact". It cannot be viewed as a one-way process: e.g. a stigmatiser decides to meet a stigmatised person. Contact is a mutual event, where the effects of stereotype confirmation in the *powerful* person are uncertain, and although some social anxieties have been overcome by the (relatively) *powerless* person, residual anxiety may distort actual social exchanges. We need to understand why Study Two defined the most potent demographic of greater contact with people with mental health problems as higher income (Table 5.2) when we know the prevalence of most of the six disorders is lower in this group. It could be that people on lower incomes are less likely to disclose mental illness to their families (Leaf et al, 1987) or the combination of lower income and mental illness leads to more reduced social networks (Thompson et al, 2004). Anecdotally, we see far more public disclosure of mental illness by better off people, typically celebrities: they rarely experience stigma's economic consequences. In Study Two, neither knowledge nor contact seemed to benefit attitudes. Study Three did link better objective knowledge to more positive attitudes, but this may be confounded by the coincidence of the knowledgeable and more positive group – doctors and medical students. An alternative paradigm to the medical model of stigma reduction will be presented in Section 7.4.

7.2 Lesson One: Redefining "distance"

7.2.1 A modern US study randomly presented one of five vignettes (major depression, schizophrenia, troubled person, and alcohol and cocaine dependence) to a general population sample (Link et al, 1999b). Five social distance statements comprised an SD score. In descending SD order, the results were (people with) cocaine then alcohol dependence, schizophrenia, depression, with lowest SD to (the unlabelled,

nonpsychiatric condition of) a troubled person (Link et al, 1999b). Although the SD questions of Study Two also revealed the worse scores for the addictions and schizophrenia, direct comparisons with this US study are not possible. Study Two agrees with a contemporary Dutch study in failing to find sociodemographic determinants of SD, and finding a strong association between SD and substance misuse (van 't Veer et al, 2006). However, the SD aspects of Study Two have not delivered enough to provide a solid evidence base for interventions: the three SD questions of Study Two bear little relation to standardised SD scales (Penn et al, 1994; Link et al, 1999; Corrigan et al, 2002). In light of the limitations set out on the "feel as they do" question (Section 5.6), Crisp et al (2005) conceded: "some interviewers reported that some respondents found this statement difficult to understand". Study Two did not include a reference category to place any SD statement in its cultural context: 60.2% of Londoners would rent a room to someone with diabetes, but only 12.5% would rent to psychiatric patients (Reda, 1996). Angermeyer et al (1997) reported 20% of their German sample would talk to a neighbour who had mental illness, where 55% would talk to a diabetic person. A RoI survey, that was not peer reviewed, recorded perceived social stigma of depression and diabetes as 60% and 10% respectively; perceived disruptiveness was 64% and 18% (Vize, 2006). Hall et al (1993) found that high rejecters of people with mental illness reject obsessional vignettes with equal vigour to those dealing with psychosis, perhaps suggesting rejection is due to unknown disruptive potential with rather than fear of the person. Such reactions have been theorised as reflecting the fact that mental illness does not fit into social norms: "uneasiness (in the potential stigmatiser) may in part be due to their own fears and insecurities, perhaps brought on by the thought that the person they are interacting with is unpredictable, and may not follow the social rules" (Hayward and Bright, 1997). Without a clear SD methodology, it will not be possible to understand these processes.

7.2.2 Public campaigns that seek to reduce stigma have the unstated aim of increasing the social networks of service users and their carers. Several possibilities arise from Study Two's findings about contact. There are circumstances and certain people where contact (regardless of degree or quality) makes no difference. We know this is true for people who have broadly positive attitudes to people with schizophrenia (the "wise" of Figure 1.1): positive dispositions are unlikely to be reduced if actual contact is ambivalent or even negative. This said, "preaching to the converted" is an important part of advertising (*keep on buying our product*) and politics (*get our supporters out to vote*). At the other extreme, in people whose negative ideas about mental illness are well formed, we cannot be certain that contact will improve attitudes. For many commercial products, advertisers speak of a *unique selling point*: what people will choose Brand X rather than buy other similar products. The quality that drives SD is a unique distancing point (UDP). To reduce stigma, the challenge is not to divide the world into nice people and stigmatisers but to identify a particular value, UDP, assigned to people with certain behaviours. Focus groups have been used successfully in advertising and politics, are be a low cost option in stigma research (Pinfold et al, 2005). These have the potential to catalogue UDP by disorder (Hypothesis 2), taking as an example the greatest challenge, the paring of schizophrenia with violent behaviour (Thompson et al, 2002). From different perspectives, parallel findings from modern Western studies are noted:

- Crisp et al (2000) report the UK public's association between schizophrenia and danger as being 70%. We reported similar proportions in NI, to a lesser extent in RoI.
- In a German public attitude study, the word *schizophrenia* invoked perceptions of danger in 70.8% of respondents (Angermeyer and Matschinger, 2003).
- A Dutch study found 74.7% agreement among the public that people who are in psychiatric treatment tend to be aggressive (van 't Veer et al, 2006).

- Philo (1996) reported that over 70% of all metal health coverage (factual and fictional, broadcast and print) features violence as a primary feature.
- Wilson et al (1999a and 1999b) identify the components which mark out people with mental illness as dangerous in prime time television: for the character, unpredictability is a strong feature, with overt threat and aggression in most. They calculated the proportion of dangerous mentally ill stereotypes as 75% of all depictions of people with mental illness (Wilson et al, 1999a).
- Gerbner et al (1981) studied prime time US television fictional characters: those with stated mental illness were more likely to be violent (73%) and killers (23%) than other characters (40% and 10% respectively).

Seventy per cent associations across attitude and media studies make the violent stereotype the exception not the rule. Even when a person's behaviour is unremarkable, a label of mental illness activates public perceptions of dangerousness (Link et al, 1987).

7.2.3 The disorder profiling approach (Table 5.8) informs the question: "what is it about people with X that drives social distance?" For each disorder, Study Two defined their UDP. UDP is complex: contrary to researchers' expectations, negative symptoms are associated with more stigma than positive symptoms (Penn et al, 2000). There may be subtle differences in UDP, for example between schizophrenia and the addictions: alongside the fear agenda, there can be an emotional / visceral response to people of disgust. High blame and PYT scores of addicts (Figure 5.4) indirectly reflect the degree of antipathy. Currently unproven, disgust may interact with fear in reactions to people with severe mental illness. If community care had been the success it was once promised to be, Western societies would not now see the associations which drive disgust: economic failure, social isolation, unsightly appearance, poverty, homelessness, and their common sequelae, alcohol and substance misuse. Complex interventions at multiple levels to challenge UDPs of fear and disgust are set out in Section 7.7.

7.3 Lesson Two: Blame and treatment pessimism do not drive stigma

7.3.1 Barry (1994) provides an historical overview of Irish attitudes towards the causes of mental illness. These began with druidic beliefs about the moon, but became more compassionate when the (pre-Christian era) Brehon Laws drew up (by today's standards) progressive codes to deal with insanity. With the Anglisation of Ireland in the Seventeenth Century, custodial approaches to insanity were adopted (Barry, 1994). In one study which attempted to develop a Beliefs Toward Mental Illness Scale, blame was one of four factors measured; it was dropped (leaving the three factors around treatment, danger and social untrustworthiness) due to lack of validity or reliability (Hirai and Clum, 2000). Blame is not a simple concept: Graves et al (1971) reported that increased beliefs about genetic transmission of mental illness were associated with greater rejecting attitudes. Angermeyer et al (2003) linked low blame / genetic aetiology beliefs to greater fear of people with mental illness. Family work had shown greater fear associated with beliefs in the illness (medical) model of schizophrenia (Smith and Birchwood, 1987). In one field study of mathematics students, showing a video based on the medical model increases participants' perceptions of dangerousness and unpredictability compared to a randomised group who saw the same patient on film, but were given a psychosocial explanation (Walker and Read, 2002). A laboratory study of the willingness of participants to give sham electric shots to confederates found that they increased the intensity of the shots more quickly if they understood the recipient's mental health problems in disease terms than if they believed they were as a result of childhood events (Mehta and Farina, 1997). Of 21 attitude studies across 9 countries, with one exception, public endorsement of biological models always predicts more negative attitudes: where psychosocial causes are endorsed, attitudes are more positive (Read et al, 2006). Rejection of the educational model by these 20 studies and Study One has an

interesting historical parallel. The enlightened reconceptualisation of (what we now call) mental disorders from possesion to illness (Section 1.3.4) led to more maltreatment in Europe and the New World. Though both demonologic and medical models characterise those afflicted as blameless, treatments for both were punitive and brutal, occasionally homicidal (Hinshaw, 2000). In short, it is consistent to have low blame for people for their illness, but to decide at other levels that the person has a spoiled identity, and act on it.

7.3.2 Disorders, principally the addictions and eating disorders, where blame remains a factor have been discussed elsewhere: Section 5.4. Corrigan (2000b) theorises that there are one of two affect-driven responses to someone who is mentally ill: (1) the symptoms are uncontrollable, they are not responsible, the affect is pity and the response is helping behaviour or (2) the symptoms are controllable, they are responsible, the affect is anger and the response is punishment of the individual. Study Two found evidence of higher blaming attitudes in NI and rural RoI for the addictions but no differences in PYT attitudes (Table 5.9). Drawing on the anthropology of Barry (1994) above and the social psychology of Corrigan (2000b), traditional Judeo-Christian beliefs about alcohol misuse may be the driving force for the regional variations in PYT scores, reflecting latter beliefs (2) that addictions are controllable, and evoke anger. Study Two cannot state whether SD towards addicts is due to blame or fear. Blame, even to a slight extent, plays a major role in self-stigma (Section 7.4): if a person perceives their condition is of their own making, then they may experience this to a greater degree and be more reluctant to disclose their difficulties or seek out help. Cooper et al (2003) have linked higher perceptions of personal responsibility with reduced help seeking.

7.3.3 Public beliefs about outcomes were also compared to health professionals': psychiatrists, clinical psychologists and general practitioners. Professionals rate long term outcomes of depression and schizophrenia more negatively than the general public

(Jorm et al, 1997a). With regard to eating disorders, high optimism about treatment outcomes recorded in the UK public sample was described by the authors in a negative light in that it indicated "trivialisation of eating disorders" (Crisp et al, 2000). When Angermeyer and Matschinger (1997) added a sentence to their schizophrenia vignette, "the person made a full recovery and was released from treatment", this made no difference to SD scores. Thompson et al (2002) concluded that: "members of the public in Alberta do not need to be told that schizophrenia is a debilitating disease, that it is no one's fault or that treatment can be very helpful". For lay people, social structural factors are central to mental health, and "many lay practices of individual coping resonate with some professional ways of working with mental health problems: shared problem solving, personal validation and cognitive interventions" (Rogers and Pilgrim, 1997). Lay assumptions about mental health are not "all or nothing" and can rarely be divided into good (the same as professionals') and bad (low MHL, mental health literacy). They show a wide variation across beliefs about aetiology, treatments and outcomes. Thirty years ago, lack of good treatments were posited as a cause of stigma by one group and the cause of mental illness by another: Section 1.4.3. Bord (1971) replicated the paradox of both Phillips (1962) and Schroeder and Erhlich (1968): the public approves of treatment but has more rejecting attitudes as the person begins to seek more help – they responded to vignettes with increasing levels of rejection from (least SD) no help sought, help from clergy, physician, psychiatrist or (highest SD) being admitted to a mental hospital. In the light of the Irish public's sophisticated differentiation of mental disorders, these findings could be explained by public perceptions of severity of illness: from the mild ("that could be me") to severe (the "hard cases"). The apparent contradiction ("treatment is a good thing and *they* should have it, but I reject *these people*") may also be explained by the public's reaction of *pity* not parity to people with mental health problems. In something as complex as societal response to people who are ill, we expect contradiction and

paradox. For example, Wahl (1999b) commented on a 1993 *Parade Magazine* general public survey where over 70% agreed that "more tax money should be devoted to caring for the mentally ill" – yet highly stigmatising attitudes prevailed in that sample. One lesson of Study Two's findings on the public's confidence in good outcomes might be to avoid explicit content about treatment benefits in public education work. On the island of Ireland at least, the argument that interventions are useful has already been won. Extravagant claims could only spoil existing therapeutic optimism: spending money on a public health campaign to highlight successful psychiatric treatments would be a waste of resources. The same "*if-it-ain't-broke-don't-fix-it*" wisdom applies to blame. Both could have unintended consequences, for example leaving the public with the same pessimism as health professionals, or *rebound* where a sceptical public question whether the campaign is hiding something else (e.g. risks of violence) from them. Perhaps a better focus should be to debate the efficacy of psychiatric interventions with sceptical service users: Section 5.6. Although professionals' language has changed, from compliance through adherence and concordance (Britten, 1998), major differences still divide service users from health and social care professionals. Better drug treatments could reduce stigma indirectly by reducing the outward appearance of illness and/or increasing signs of better social functioning (employment, appearance, status).

7.4 Lesson Three: an Inside Out Model of Stigma

7.4.1 By their natures, Studies Two and Three are empirical studies, examining knowledge and attitudes from the outside in. By contrast, we learned more about the experience of people with psoriasis from the PLSI, combined with quantitative measures, than about the experiences of encountering someone with mental illness or a patient requiring ECT. Taking an inside out approach is not new to stigma research, not least narrative-based accounts (Section 1.3; Box 1.1). Anthropologists have attempted this

too: the Explanatory Model Interview Catalogue, EMIC, elicits narrative responses that include items on disclosure of mental illness and self-stigma (Weiss et al, 2001). Rusch et al (2005) describe three pathways of stigma, based on two factors, group identification (with the stigmatised out group) and the perceived legitimacy of stigma: Figure 7.1. If group identification is low, someone with mental illness reacts to stigma with *indifference*. To this group, we can also add people who have mental health problems but who are either unaware of these and / or deny they are caused by "mental illness": 37% of adults with schizophrenia in one study (Pyne et al, 2001). It is useful to conceptualise the unaware group (not unlike the aware of Figure 2.3) and those who deny mental illness. There are many good reasons to resist a psychiatric label: abhorrence of group identification, resistance of the aggressor (the custodial psychiatrist), loss of face, status loss etc. These are at once markers for the effects of stigma (Table 1.1) and manifestations of control over care policies (Section 7.5.2). When patients attribute psychosocial stressors not illness as the cause of their admission, they protect themselves from stereotypes (Sayce, 2000). This combined group are *indifferent* to stigma though there is good evidence that stigma will impact upon them regardless of their indifference (Table 1.1). If group identification is high, the second factor (perceived legitimacy) determines the final two pathways. Low legitimacy leads to *righteous anger* and empowerment: the person might actively challenge stigma and discrimination against themselves and others. High group identification and high legitimacy lead to *self-stigma* (Rusch et al, 2005). Without this inside out perspective, anti-stigma campaigns would inevitable focus on, and indeed exclusively work with, the *righteous anger* group. They would fail to inspire the *indifferent* group and pursue "top down" solutions (media, schools, laws) to the detriment of the *self-stigma* group who lack empowerment but not indifference to the challenge of stigma.

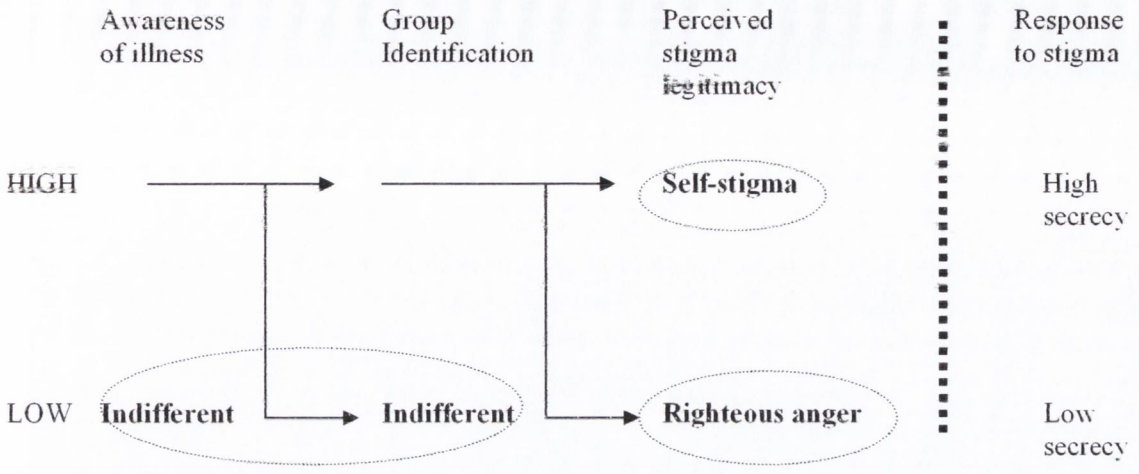

Figure 7.1: Three groups of discreditable stigma after Rusch et al (2005).

7.4.2 Of the three studies, Study One touched most closely on an understanding of how an individual evaluates social interactions, cognitively and emotionally. Findings divided people with psoriasis into two groups, those with high and low perceptions of stigma: (Table 4.6). Table 7.1 sets out possible explanations as to how attitudes impact on behaviour and thereby on affect. This approach is also applied to the six disorders. Evidence has been set out elsewhere (Section 1.4) that even if the observed person does not display any stigmatised behaviour (a person known to have had depression is fully well) or does not have the disorder (the "normal" person of field studies), negative assumptions may still be activated in the observer. The same appears true for recipients of stigma: (Table 7.1). Anecdotally, many service users who have regained their mental health, describe wishes to be invisible, to have "a day off from it all" – so that social contacts can occur without activating self-stigma, an outrider for the illness itself (Table 7.1). Placing people with psoriasis and psychiatric diagnoses into the same

Table 7.1 An inside-out model of contact between people with mental health problems and potential stigmatisers

Disorder	Anticipation of contact	Action	Outcome of contact for individual	Type of stigma
Psoriasis with low perception of stigma	No fear of negative evaluation	Usual social interactions	Positive or neutral outcome	None
Psoriasis with high perception of stigma	Fear of negative evaluation	Covering up Avoidance of others, Anticipatory anxiety	Increased anxiety. One third of sample (Study One) increased alcohol consumption	Self-stigma (Stigma of alcohol misuse)- minimal
Alzheimer's dementia with insight	Activation of anxiety about forgetfulness	Avoidance of others, Anticipatory anxiety Confabulation	Reinforcement of anxiety	(Self-Stigma)- minimal
Depression	Preoccupation with perceived failures, low self-esteem, automatic negative thoughts e.g. of rejection by others.	Avoidance of others Activation of "worst case scenario" fears	Negative assumptions activated. Guilt feelings	Self-stigma (Stigma) - minimal
Schizophrenia	Jumping to conclusions, misinterpretations, missing social cues. Assumptions that new contacts will react with caution to them and / or cue their fear	Avoidance of others Avoidance by others Testing of dysfunctional hypotheses	"Paranoid" hypotheses confirmed as new contacts respond to their apprehension with apprehension	(Self-Stigma)- minimal Stigma
Anxiety	Fear of negative evaluation and activation of anxiety symptoms. Assumptions that new contacts will observe their anxiety	Avoidance of others Anticipatory anxiety	Reinforcement of cycles of anxiety Lower self-esteem	Self-stigma (Stigma) - minimal
Drug / alcohol addiction	Fear of negative evaluation / blame, guilt feelings Others may cue their fear	Avoidance by others Avoidance of others Self-medicate; drink	Fear of social contact and cycle of anxiety-addiction reinforced	Self-stigma Stigma
Eating disorders	Negative assumptions that others will judge appearance as fat, unsightly; of blame by others	Avoidance of others Covering up	Negative assumptions confirmed	Self-stigma Stigma

context invokes Goffman's categorisation of stigma (Goffman, 1963). A discredited group cannot hide their stigmatised physical appearance (race, physical disability, facial disfigurement) while the discreditable group can attempt to conceal it (all categories of Table 7.1). To conceal is to trigger self-stigma, reinforcing its affective consequences and the self-belief that "something is wrong with me". This model (Table 7.1) reflects the interaction between the effects of the disorder and how individuals react to events (e.g. contact). It explains cycles of addiction, and the reinforcement of negative assumptions in people with depressive, anxiety and eating disorders. Its model for dementia is presumptive, but for psychosis, it fits with recent reconceptualisations of cognitive processes (Garety et al, 2005). Some of the core symptoms of depression (lower self-esteem and confidence, guilt, reduced interests) are mediated by social mechanisms, and, as yet unproven, may be diminished in people with depression who live in unsupportive environments. For every disorder, the challenge remains to separate the effects of illness from those of stigma (Tables 1.1 and 7.1). Levy (1993) describes stigma management as a combination of information control (disclosure guidance, reframing stigmata and selective association strategies) and dissonance induction. This latter strategy "helps clients to develop behaviours that directly or indirectly evoke others' sense of fair play, justice and compassion" (Levy, 1993). Aside from the pressure placed on an individual to counter the effects of stigma on his/her own, such responses, if pity is evoked, this will reduce self-esteem (Blaine et al, 1995). A comprehensive disclosure and support model, written for service users, is set out by Corrigan and Lundin (2001).

7.5 Lesson Four: Hearts not minds

7.5.1 Interactions of the three attitude components (Section 1.6.3) underpins the three studies. Tracing the genesis of attitudes has also uncovered paradoxes of behaviour: drinking more despite alcohol making psoriasis worse, contradictory attitudes to people

with mental illness and inconsistent application of ECT knowledge. One finding common to three studies has been to move attitude formation from the realm of scientific certainty (tell people with psoriasis that others *should* accept the physical manifestations of their illness, or knowledge *always* improves negative attitudes to people and treatment), to more emotional reactions – the latter options of Figure 2.2. In the arena of mental health, we all hold some attitudes which do not withstand scrutiny, and where objective fact is overridden by belief, frequently affect-driven. ECT attitudes of nursing students' who saw someone have a supervised seizure did not change their evaluation of the treatment – as opposed to the procedure. By contrast, identical contact among medical students seems to benefit their knowledge and attitudes in Study Three and others (Table 2.5). As with more rigorous definition of contact (Section 5.5), future studies might examine the reality of the nursing student who experiences the prescription and procedure of ECT. Qualitative methods would establish whether its prescription is perceived as coercive, its short term side effects (confusion, memory difficulties) excessive, or the design of teaching programmes dies not allow reflection on its benefits. Study Two reported members of ABC1 as significantly more knowledgeable and optimistic about schizophrenia treatment, but had higher perceptions of danger from people with schizophrenia than lower income respondents did (Table 5.9). Others have cast doubt on the proposition that wealth is directly proportionate to the integration of people with severe mental illness. Taylor and Dear (1981) studied Toronto residents' attitudes to the location of psychiatric residential care homes. Their unexpected finding was that (inner city) *acceptor* neighbourhoods had low social cohesion, but *rejectors* (the more affluent suburbs) had higher cohesion. Wolff et al (1995b) identified negative attitudes in middle class respondents in their south London study. Relevant to a now prosperous Ireland, work from the former East Germany shows negative attitudes there as increasing since reunification (Angermeyer and Dietrich, 2006). That more knowledge does not mean

less stigma (Study Two) or less antipathy (Study Three) reflects the truism of Hoggart (2004): "greater knowledge may just as easily lead to greater dislike – to know all is not to forgive all. Information is in itself inert. It may lead to knowledge only if it has been considered, ordered, assessed. Does knowledge lead inevitably to the acquisition of wisdom? T S Eliot was right when he asked where was the wisdom we have lost in knowledge or the knowledge we have lost in information?"

7.5.2 Section 7.2.2 set out the 70% consensus as embodied in the violent psychokiller stereotype. At the cognitive level, we can argue against the 70% assumptions. The key messages here are: (1) risk is remote: more UK people are killed each year by speeding police cars than by people with mental illness, and a study of 40 years' UK homicides show that "mental illness killings" are constant, and decreasing as a proportion of total homicides (Taylor and Gunn, 1999); (2) risk is relative: Coid et al (2006) measured the attributable risk of violence to others by someone with psychosis as 1.2%, but this rises to 21.7% and 29.8% in alcohol and drug dependence respectively – and to over 50% in people with harmful alcohol use (3); these risks are defined by the environment into which we place people with severe mental illness (Steadman et al, 1998); (4) people who misuse alcohol and substances have risks independent of psychiatric symptoms (Steadman et al, 1998) whereas up to 10% of people with psychosis present a small risk of violence mostly when they are unwell; (5) increasing social distance will further isolate users, making nonadherence and relapses of illness more frequent (Link, 1998): more stigma will increase substance misuse and failures to accept effective treatments more likely; and (6) diagnostic psychiatric manuals such as DSM have increasingly included violence as a "symptom" of mental disorders in recent years: DSM-II had 2.7% of all disorders that included violence as a criterion, but this rose to 26.2% in DSM-III (Harry, 1985). An additional argument centres on recent facts about the real violence issue is not violence by, but violence to, people with schizophrenia (Goodman et al, 2001 and

Honkonen et al, 2004). A 33% lifetime prevalence of assault (sexual in women, physical for men) was reported across 4 US states (Goodman et al, 2001), and the same factors (poverty and substance misuse) drove the increased risk of violent victimisation (Honkonen et al, 2004). From a psychobiological perspective, violence trumps other beliefs about people we do not know (Kurzban and Leary, 2001), higher fear of people with mental illness was linked to young couples with children (Wolff et al, 1993b). Jeremy Laurance (2002) concluded: "belatedly we have come to realise that community care involves a range of measures to promote social integration. That means help with jobs, money housing, relationships, neighbours and social skills. It means a focus on prevention and mental health promotion, rather than crisis intervention". He looked at the totality of health and social services and judged the government framework one of "control over care". What links both Glasson (1996) and Laurance (2002) is that when they write directly about mental health in relation to UK Government policy, they frequently cite not the policies and outcomes, but the public's *perception* of them. These have been summarised: "in many situations today, mental health professionals striving to maintain good quality services to those most in need, find themselves up against an iron triangle formed by public anxiety and distrust, an alienated tabloid press, and government policies increasingly focussed on quick-fix populist measures, whilst at the same time pursuing longer-term goals of asset-stripping and withdrawal of state responsibility." (Cooper, 2001).

7.6 Lesson Five: Rethinking contact

7.6.1 A near consensus finding from 61 public attitude studies of the past 15 years has been the positive effects of contact on attitudes (Angermeyer and Dietrich, 2006). Study Two did not confirm the contact hypothesis, nor did a contemporaneous Dutch study that rigorously defined contact (van 't Veer et al, 2006). Complexities of measuring contact have been discussed (Section 7.1.2), but contact needs to be considered other than as a

favourable risk factor (e.g. higher income equals more contact). Firstly, contact is context-specific: this determines the power differential, the rules of behaviour and the degree of intimacy involved. Experiences could be buying a newspaper, applying for a job, or disclosure of illness to others. Secondly, it is disorder-specific: meeting an addict is different to someone recovering from depression. Thirdly, powerful emotions mediate the interaction: Table 7.1. For Link et al (2004), reactions in the in-group are anger, irritation, anxiety, pity and fear; and in the out-group shame, embarrassment, fear, alienation and anger. Fourthly, emotions change actual behaviour during contact: if a person with schizophrenia detects anxiety in the other, s/he speaks more softly and slowly, but this adds to the observer's fears. Fifthly, contact has multiple outcomes for both parties: no outcome, subtle positive outcome (rejection of stereotypes by both), subtle negative outcome (assumptions activated or stereotypes confirmed), positive outcome (friendly exchange, job offer, validation for "coming out" and disclosing mental illness) or negative outcome (discrimination in all its forms: Table 1.1). Finally, contact is part of wider group interactions (Section 1.5.2), for example group identification (Section 7.4.1). Well meaning actions of the wise can have the rebound effects, that is, rejection of "new" information and confirmation of existing prejudices (Penn and Corrigan, 2002).

7.6.2 Interventions that neglect these six dimensions (the anti-stigma equivalent of speed dating) will fail. Given the challenge of making contact successful, research has turned its gaze onto participants from the in-group: just as Study Three inferred relatively fixed negative attitudes among the nursing group, in their review of contact, Kolodziej and Johnson (1996) saw mental health professionals as having stigmatising attitudes that are harder to shift. Overall, they noted interventions can succeed even if they are brief, and that contact tends to reduce negative attitudes rather than increase positive ones. Corrigan and Penn (1999) summarise the evidence on **positive contact**:

- there is equal status between participants (Section 1.1.1)
- cooperative tasks define the intervention (shared tasks are likely to reduce power differences between participants further)
- there is institutional support for contact (the institution needs to make it clear it does not support the status quo of *them* and *us*: Section 1.4)
- people with mental disorders do not greatly deviate from the stereotype (i.e rebound stigmatisation is avoided by presenting unrealistic role models: Section 1.5.2).

To combine observations of social interactions that include insiders' perspectives with a deeper understanding of processes, qualitative research will be needed. Stigma pioneers, notably Goffman, used qualitative methods, subsequently quantified by others (Section 2.5). In relation to the *don't knows* and *don't-want-to-knows* (Section 5.4.1), qualitative work would help to establish what factors obstruct low-level contact, and ultimately impair full community integration of people. Qualitative research is more accessible to nonresearchers, and adds another compelling reason to involve service users, on equal terms, in future research. That users' discrimination research underrepresents the effects of stigma (Section 1.4) is also addressed by user-led interventions. To date there has been little qualitative work examining deep-rooted emotions of the in-group. Experiments have measured reaction times when a member of the out-group is introduced to them (Dovidio and Gaertner, 2000).

7.7 Coordinated strategies to reduce stigma

7.7.1 Improved research models have been listed above. Wahl (1999) provides an inside-out scale, and Thornicroft and others (2006, personal communication) are working on an instrument to measure discrimination across multiple parameters. New research measures stigma as actual behaviour: signing a petition objecting to media stereotypes (Corrigan et al, 1999) or providing a contact phone number for future participation in a seminar with users (Penn and Nowlin-Drummond, 2001). Corrigan et al (2004) examined

resource allocation intentions and attitudes to mental illness in 54 volunteers, but invited participants at the end of the study to donate to a US mental health charity. Total donations were inversely related to negative attitudes (Corrigan et al, 2004). Other tentative moves have united stigma researchers with users' groups to integrate research better into interventions (www.openthedoors.com and www.stigmaresearch.org).

7.7.2 Interventions can be divided into two broad areas. Firstly, **macro** interventions are broadly-based initiatives that will influence most parts of society. They could address the *don't know / want to know* groups, with minimal knowledge components, for example, challenges to conventional wisdom of the 70% violence consensus. More may be achieved by appeals to individuals' sense of justice than logic (Corrigan et al, 2005). Five lessons and a number of key target attitudes are set out above. Public attitude surveys establish baselines, and added to this effort, the advice of marketing experts, pollsters, and health economics' scientists is essential. It took decades of innovative government policy (belated resistance of the powerful tobacco lobby plus direct funding), media campaigns, school initiatives and public debate to change deeply-ingrained attitudes to smoking. Major shifts in public opinion and behaviour need not take a generation: climate change has moved from a minority concern, through public scientific debate through to the top of governments' agendae. Successful media interventions, including network and MTV (Music Television) advertising have been described with specific mental health messages (Hinshaw, 2000). Secondly, **micro** interventions are bottom up and happen locally. Central to these is an understanding of the UDP factors that prevent a community from social engagement from someone with severe mental illness. Micro interventions must start with analysis of UDPs as obstacles, and then construct circumstances in which contact, based on a modified contact hypothesis, can promote integration over stigmatisation. Clinicians should initiate micro interventions in individual patients (Section 5.7) but there are other important target groups. Two

innovative interventions in schools are described by Pinfold et al (2003) and Schulze et al (2003). Between the macro and the micro, other **intermediate interventions** are possible. Removing obstacles to employment with coordinated supports to return people back to work are the best example here: these will not be successful without macro and micro initiatives. Whatever interventions are made, their effects must be measured – not just on the public but the end recipients of their efforts. It is not just that previous large-scale interventions have had poor methodologies, or even that they were top-down once-off efforts, the issue is that they did not work.

"The truth is we have still not accorded value to people with mental health problems on anything like the same basis as other citizens; we still see them as 'undeserving'. There is a historical change in progress. How fast that change happens depends on the energies and commitments of people who want it to happen and our pooling of our understanding of how to achieve it... Work now to improve civil rights laws and to build new understandings may appear, in retrospect, to be a major step towards getting rid of films and press articles about 'psychos' and rates of employment among user/survivors of barely over 10%. One day these may seem almost unbelievable pieces of historical barbarism" Sayce (2000).

"I am told that my brothers find it extremely painful to reconcile their memory of the vital and charismatic figure whom they admired with the broken and confused character I became at the age of 20... in this narrative I have done no more than relate my life experience. If my story sheds any light on the life of a paranoid schizophrenic illness from a patient's standpoint and thereby helps my fellow sufferers, I shall feel my life has been the more worthwhile. I think I shall enjoy a couple of pints of Guinness this evening; maybe in the morning I shall at last recognise the man in the shaving mirror as an old friend" Scott (2002),

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