

Schizophrenia and the Self:

Rebuilding and Maintaining Identity After a Diagnosis of Schizophrenia

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For Suenneli and Bubbles

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Abstract

Schizophrenia is a debilitating mental illness that strikes approximately 1 in 100 people in the population during their lifetimes. It is an illness that can have a severe impact on the sense of self of people affected. It is the purpose of this thesis to examine the processes by which such a sense of self is disrupted, rebuilt and maintained in people diagnosed with schizophrenia. Twelve people diagnosed with schizophrenia were interviewed with regards to the ongoing impact of their illness. In particular, interviews focused on processes relevant to their sense of identity before, during and after the diagnosis of schizophrenia. The thesis also thematises issues of power and social structure surrounding the person diagnosed with schizophrenia.

It was found that, after medication, a number of social processes were important to rebuilding a sense of identity. These included the development of illness narratives, interaction with family and friends, illness management, life management, the setting of life goals and, in some cases, participation in organised religion. Identity was typically maintained through processes of stigma concealment and passing. The influence of psychiatrists, psychopharmaceutical companies and a deinstitutionalised environment in which severe mental illness is treated all emerged as significant factors in the process of rebuilding a sense of identity.

The thesis seeks to make contributions to the sociology of schizophrenia and severe mental health concerns more widely. In particular, it deploys concepts of biographical crisis to make sense of the intensity of identity disruption people diagnosed with schizophrenia may experience. It also seeks to revise the perspectives of symbolic interactionism and phenomenology to better understand the emotive and embodied nature of identity processes in schizophrenia. Beyond this, the thesis explores the relationship between language, power and agency and its significance in shaping the experience of the patient diagnosed with schizophrenia. The concept of negotiated power networks is put forward to help make sense of these power relationships in a deinstitutionalised environment. Finally, the thesis proposes the concept of identity work as a way of understanding the operations of agency and relevant processes affecting identity.

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CHAPTER 1

Introduction

Schizophrenia is a debilitating mental illness that strikes approximately 1 in 100 people in the population during their lifetimes (Sadock and Sadock, 2007). The illness strikes regardless of class, gender, sexuality or ethnicity. It can seriously affect cognition, emotion and behaviour in the sufferer. Schizophrenia, and accompanying treatment, can cause significant damage to the sufferer's identity; to his or her capacity to project and maintain a viable self. It is also an illness over which psychiatrists, mental health workers and psychopharmacologists exert significant influence.

The latest Diagnostic and Statistical Manual of Mental Disorders [the DSM] released by the American Psychiatric Association [the APA] (5th Edition, 2013, p. 87¹) suggests diagnostic criteria for the "schizophrenia spectrum" of disorders; that is, disorders involving a schizoid or psychotic element:

Schizophrenia spectrum and other psychotic disorders include schizophrenia, other psychotic disorders, and schizotypal (personality) disorder. They are defined by abnormalities in one or more of the following five domains: delusions, hallucinations, disorganized thinking (speech), grossly disorganized motor behaviour (including catatonia), and negative symptoms.

Schizophrenia itself receives more precise diagnostic criteria (APA, 2013, p. 99):

- A. Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated). At least one of these must be (1), (2), or (3):
 - 1. Delusions.
 - 2. Hallucinations.
 - 3. Disorganized speech (e.g., frequent derailment or incoherence).
 - 4. Grossly disorganized or catatonic behavior.
 - 5. Negative symptoms (i.e., diminished emotional expression or avolition).

¹ Note that the DSM has been criticised as a tool for defining severe mental illness. See for relevant discussion of the DSM series and psychiatric illness classification generally, Helzer et al., 1977a, 1977b; Schacht, 1985; Eysenck, 1986;. Faust and Miner, 1986; Garfield, 1986; Rothblum et al., 1986; Harvey, 1987; Zimmerman, 1988, 1990; Caplan, 1990; Boyle, 1993; Andreason and Carpenter, 1993; Kirk and Kutchins, 2008. See for a philosophical perspective Bolton, 2001.

Further criteria stipulate that “[f]or a significant portion of the time since the onset of the disturbance, level of functioning in one or more major areas, such as work, interpersonal relations, or self-care, is markedly below the level achieved prior to the onset”; that “[c]ontinuous signs of the disturbance persist for at least six months”; that “[s]chizoaffective disorder and depressive or bipolar disorder with psychotic features have been ruled out”; that “[t]he disturbance is not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition”; and “[i]f there is a history of autism spectrum disorder or a communication disorder of childhood onset, the additional diagnosis of schizophrenia is made only if prominent delusions or hallucinations, in addition to the other required symptoms of schizophrenia, are also present for at least 1 month (or less if successfully treated)” (APA, 2013, p99).

Current research suggests that some people possess a significant disposition to schizophrenia that may be “triggered” by certain stressful situations. Research also suggests that this disposition may be related to genetic factors. Today the illness is most commonly understood, and researched, on the premise that it is a brain disorder. That is to say, schizophrenia is understood to originate in one or more of the following: faulty brain structure, chemical imbalance in the brain or abnormal brain process. Many explanations for schizophrenia involving the brain have been offered, although none has yet identified with certainty the biochemical process behind the illness. In the meantime, psychiatrists use psychotropic medication as the first tool of treatment, while sufferers generally adopt the language of medication names, of “symptoms” and “side-effects”, and the general description of their illness arising from a “chemical imbalance” in their brains.

At this point, we may make a contribution to the understanding of schizophrenia by looking beyond a purely bio-chemical approach. Diagnosis and treatment, usually with medication, is both a biochemical intervention and a social process. The history of diagnoses and treatment (such as that offered by Michel Foucault in *Madness and Civilization*, 1988) contributes to a sociological

understanding not only of madness, what it is and might be, but also how it is construed and related to larger social structures and historical trends. The language adopted to describe and account for illness may be subject to sociological analysis (McLaughlin, 2009; see, for example, the use of specific terminology to delineate people in the mental health sector Stephens and Belisle, 1993). Various attempts have been made to seek a social or sociological cause for schizophrenia, particularly focusing on inconsistent communication (the “double bind”), or disturbed interpersonal relationships in childhood (Bateson et al., 1956; Sullivan, 1962) , or on the disparity between “true” and social identity (Cooper 1970; 1971) (although many such efforts have been contradicted by more recent developments in the field (Shorter, 1997, p. 176, 240, 244; Sadock and Sadock, 2007, p. 475)). When dealing with the conglomeration of institutions affecting the person diagnosed with schizophrenia – what is termed in this thesis the “psychiatric apparatus” – people with schizophrenia follow certain patterns of interaction and deference, or sometimes resistance, that require a sociological perspective. Resistance to Community Treatment Orders and enforced medication illustrate a situation of power that sociological thought may explore. The return by people with schizophrenia to a state approaching normalcy is very often achieved through a social process of action, interaction, meaning and intention. Interaction with friends and family may have a significant effect on illness outcomes. Such processes, vital to recovery, are also amenable to sociological imagining. Furthermore, interactions with members of the public may involve significant experiences of stigma or efforts towards stigma concealment; processes analysed sociologically so well by Erving Goffman (1963) in *Stigma*. There undoubtedly exists a stigma around major mental illness in Australia, particularly in relation to schizophrenia (Burdekin, 1993, Bakshi et. al, 1999; Epstein et al., 2012. For all these reasons sociology can not only provide an insight into the experience of schizophrenia, but it may also in fact prove indispensable to fully understand the illness.

A sociological approach to schizophrenia may take many tacks. One may attempt a sociological history of the subject. One may interrogate the development of classifications of mental disorders

(Black and Boffeli, 1989); develop a political economy of schizophrenia (Warner, 1985); explore differing cultural conceptions of psychiatric disorders (Mercer, 1986); or investigate the relationship between schizophrenia, the law and incarceration (Cockerham, 2006; Rogers and Pilgrim, 2007; Murray et al. 2006). Whatever perspective we consider, however, most researchers agree that there has been a lack of study *from the perspective of* the person diagnosed with schizophrenia (Scheper-Hughes and Lock, 1986, p. 137; Estroff, 1989, p. 191; Strauss, 1989, p. 179-181; Cook and Wright, 1995, p. 106; Markowitz, 1998, p. 344; Williams and Collins, 1999, p. 61; Chenoweth, 2000, p. 93; Gove, 2004, p. 372). In light of this lacuna, this thesis seeks, via the qualitative sociological method of semi-structured interviews with a limited number of people, to study schizophrenia from the perspective of the person diagnosed. Through these interviews, the thesis aspires to explore the impact schizophrenia, diagnosis and treatment can have on people diagnosed with schizophrenia; to give voice to a group of people who are generally silent.

The researcher was greatly helped in this endeavour by the fact that he himself was diagnosed with schizophrenia in 2003, and has lived with the condition, medicated, since then. This position as a “consumer researcher” has proved invaluable to the process of the thesis. It has helped immeasurably in the creation of trust and mutual recognition with interview subjects. It has allowed the researcher to gain a personal insight into descriptions and analysis of symptoms, diagnosis, hospitalisation, medication and stigma. It has encouraged empathy to emerge for the more difficult symptoms and aspects of schizophrenia. It has also helped provide a degree of respect for the individual stories of interviewees (on “insider” and “outsider” knowledge see Merton, 1972).

In drawing out the stories of interviewees, this thesis focuses upon two themes pertaining to the perspective of the person diagnosed with schizophrenia: identity and power. In many ways the theme of identity comes naturally to a sociological approach to schizophrenia. Sociology has classically shown great interest in issues of identity (Leary and Tangney, 2003). Georg Simmel (1958)

accounts for society with a picture of interacting subjects and identity emerging in different forms and types of social relation. Stuart Hall (1971) examines the play of power and exclusion in the construction of identity. Anthony Giddens (1990, 1991) contemplates identity in relation to modernity and beyond. Perspectives such as “symbolic interactionism” developed by George Mead and Herbert Blumer (used later in this thesis) focus on issues of identity and social interaction; on the need to understand the rebuilding and maintenance of identity as an ongoing process.

However, this thesis departs from these recognised investigations of identity by focusing on the theme of *identity disruption*. Schizophrenia is defined first and foremost by the experience of disruption (Dinos et al., 2005). Such disruptions are often expected of chronic illnesses generally; Michael Bury makes this point in his 1982 article, “Chronic Illness as Biographical Disruption”. Moving beyond Bury, however, we can observe that schizophrenia is *itself* an illness whose impact may bring with it a significant interruption to identity. People suffering schizophrenia may suffer delusions and hallucinations that disrupt their sense of self. They may believe, for example, that their body has been replaced by a non-living substance, or that they are an historical figure, or may wish for or attempt suicide (the ultimate negation of identity). They may lose the ability to engage sensibly with those nearest to them. Indeed, in light of the disruption schizophrenia can cause I suggest the alternative terminology of “biographical crisis” and (as we will see below) “ontological insecurity” as ways of conceptualising experiences of identity breakdown in schizophrenia.

To approach the question of self from the point of view of the schizophrenic subject is to challenge some of the formative premises of sociological theories of identity. These theories typically posit a “functioning” self. Symbolic interactionism, for example, devotes some time to the socialisation of infants but, in adults, assumes an effective and operative identity. However, in the sociological study of schizophrenia – such a disruptive illness – this becomes a significant problem: here we must interrogate how identity *malfunctions*, and how a *broken or disrupted* identity is made whole again.

Significant time in the interviews and discussion for this thesis is given over to a discussion of themes of how identity is “rebuilt” and “maintained”. Indeed, this thesis begins with the question: *How do people diagnosed with schizophrenia maintain or re-establish their identity in the context of their illness, diagnosis and treatment?* In light of this problem, this thesis also makes a reflexive contribution to symbolic interactionist theory, leading to the suggestion that incomplete identity may be labelled and understood as “compromised interaction”.

This thesis makes a further contribution by understanding identity as a phenomenon resulting not only from symbolic or discursive processes, but as deeply embodied. Identity must be understood not only as a symbolic process affecting the mind as an abstract system, but also as a phenomenon that is inherently situated in a material and sensorial world. This embodied dimension of identity and its breakdown becomes clear in many of the symptoms a sufferer of schizophrenia may experience. Hallucinations or delusions may occur that may be thought of as breakdowns in the embodied, sensory self. Work by Laing (1990 [1960]) suggests that people with schizophrenia may experience their sense of self as struck by “engulfment”, “implosion” or “petrification”. Again, however, many traditional accounts of identity formation and maintenance fail to account for these embodied aspects of the self. Symbolic interactionism, for example, focuses on the discursive and semiotic level of language and gesture in the development of viable selves. In light of this issue, this thesis contributes to the relevant literature in two ways. The first is to explore ways we may expand symbolic interactionism to account for embodied experiences. This involves investigating what an “embodied interactionism” or “emotional interactionism” may look like. As we will see, embodied interactionism allows for an additional, emotive layer of interaction, expressed not only through symbolic language, but also the language of the body (“body language”). Significant gestures and symbolic interaction are provided with context, colour and content by the emotional state of interacting individuals. The second contribution emerges through an analysis of phenomenological accounts of identity and being. Although these accounts vary, they tend to all focus, to some extent,

on the disruption of being caused by schizophrenia. Such accounts, in particular that given by Maurice Merleau-Ponty (1962), also establish that the human being is ontologically invested in the world; that he or she is emotionally tied or directed to certain projects and this dedication emerges through an embodied, sensory consciousness. When a breakdown of this relation occurs in schizophrenia, this is necessarily a sensorial or bodily event.

Laing's (1990) concept of "ontological insecurity" speaks to the third area of sociological enquiry in which this thesis seeks to intervene. Where traditional accounts, such as those provided by Bury (noted above), establish that chronic illness may involve a disruption, the actual level of disruption in schizophrenia may take on an ontological status. Again, Laing and Merleau-Ponty, among others phenomenologists such as Ludwig Binswanger and Eugene Minkoski, suggest that people with schizophrenia are generally not experiencing a simple chronic illness, but are in fact engaged in a profoundly compromised state of being; an experience of "ontological insecurity"; a disruption of the ontology of the self. With that point made, this thesis also confronts the shortcomings of phenomenology in accounting for the full experiences of schizophrenia (Cf. Rulf, 2003). While phenomenology can offer a detailed description of ontological insecurity or breakdown, phenomenologists have not generally focused on processes of *rebuilding* that a person may engage in after an ontological break. Such processes are the key focus of Chapter 7, and are of vital interest to this thesis. They are named and explored in the Discussion Chapter, Chapter 9, as forms of "ontological renovation".

The theme of renovation, of rebuilding a disrupted identity, resonates strongly with a further focus of this thesis: the concept of "identity work". The concept is developed as a contribution to the literature regarding the reformation of biography in chronic illness and schizophrenia. Identity work comes to encompass all the activity undertaken by the diagnosed person to re-establish and maintain his or her identity after the period of disruption. Typically, as suggested by the symbolic

interactionist perspective, such identity work involves the internalisation of the views of others. In particular, people diagnosed with schizophrenia must adopt and internalise the view of the general other. Identity work may extend to the activation of friendship networks and family connections. It may broadly be considered to also involve the development of “illness narratives” (Bury 2001; Cf. Williams 1984) that try to make sense of disrupted experiences. Such narratives often include the adoption of psychiatric language, identified above - medication names, “symptoms”, “side-effects” and “chemical imbalance” – to help project order over a disordered experience.

It is perhaps at this point – where people with illness adopt the discourse of the psychiatric apparatus – that the second broad theme for this thesis should be introduced: *power*. Power saturates the experience of treated schizophrenia. The patient with schizophrenia enters into a power relationship with his or her psychiatrist. Mental health nurses may exert power in clinics or psychiatric wards. In extreme cases, people may be committed to and medicated involuntarily in clinics or wards. The second half of the research question asks: *How do relations of power inform this process?*

In writing of schizophrenia and power, the shadow of “the asylum” looms large. Perhaps the best historical exploration of the asylum as a “total institution” lies in Goffman’s (1961) *Asylums*. Theorists of power and psychiatry – in particular those dealing with the idea that psychiatric practice is a form of “social control” (such as Thoma Szasz, 1974, or Allan Horwitz, 1982) – have looked to the asylum as the paradigm of psychiatric power. Even Foucault’s concept of the “disciplinary” institution (1977) seems best applied to the asylum. Indeed, stories of involuntary commitment to, and treatment in, clinics and wards do emerge from some of the research. Likewise, this thesis contributes to the Foucauldian literature by proposing the concept of “languages of resistance” that an agent dealing with schizophrenia may express.

However, in an important sense, the age of the asylum may be over. In the 1970s and 1980s, a reform process known as “deinstitutionalisation” occurred in Australia seeking to return people with mental illnesses to accommodation in the community after initial treatment. This process occurred sometime earlier in the United States (Brown, 1985b). To a large extent, this process of deinstitutionalisation was permitted by the development of fairly effective anti-psychotic medication that patients could self-administer in a non-institutional environment. This study has been undertaken in a context where deinstitutionalisation has taken place. In such a context, the chains of the asylum and the threat of psychiatric panopticism have to a large extent faded away. And yet, persons interviewed still met with psychiatrists or nurses, still followed treatment regimes, still understood their illness through the biomedical “paradigm” (Kuhn, 1996) or psychiatric terminology and still often endured significant personal isolation. It seems that some new form of power or domination has emerged. This thesis seeks to make a contribution to sociologies of power and schizophrenia by examining just what such a form of domination may entail; the term “negotiated power networks” is developed and explored to help achieve this task.

These new forms of power also emerge in the language people diagnosed with schizophrenia use to describe, make sense of and deal with their condition. Such language absorbs the diagnosed person in a web of power and agency. In particular, the use of psychiatric discourse enlists the speaker in a Foucauldian relationship of power/knowledge with their psychiatrists. However, just as the use of professional discourse illustrates the influence of the psychiatric apparatus, this thesis argues, so too do “languages of negotiation” and “languages of negotiation or resistance” emerge, illustrating a form of subjective agency that is not well developed in Foucault’s work. Furthermore, the frequent use of the term “consumer” as a self-description by people taking psychiatric medicine speaks to the influence both of the mental health support movement seeking to avoid the stigma of terms such as “schizophrenic” or “mad” (McLaughlin, 2009), and the impact of market-based mechanisms on conceptions of mental health treatment. Finally, the use of “illness narratives” by people diagnosed

with schizophrenia can help make sense of a healthy self gone wrong – forging a personal healing of the temporal breach of schizophrenia. Such language use also often portrays the diagnosed person as the active subject of the narrative, effectively establishing agency through language and moving beyond a deterministic account of schizophrenia and the pharmaceutical complex.

We may also certainly say that the new power relationship is shaped by the development of anti-psychotic medication under the influence of psychopharmaceutical companies. In light of such influence, this thesis intervenes in the literature to make the argument that the “psychopharmaceutical complex”² has colonised psychiatric practice. Diagnosis is carried out primarily as a prelude to medication, and medication is understood as the first and most important element of treating schizophrenia. Certainly Nikolas Rose (1992) emphasises the emergence of market-based systems of welfare in advanced liberal democracies and situates the rise of the psychopharmaceutical complex as part and parcel of this process. In terms of the influence of the psychopharmaceutical complex over patients, this thesis looks again to the knowledge patients carry of their medication names and their common conceptualisation of mental illness as a “chemical imbalance” in the brain. Along with negotiated power networks and the psychopharmaceutical complex comes a biochemical understanding of the self and of illness – the “biochemical self”. These aspects of power and schizophrenia are explored in both the Results Chapters, Chapters 6,7 and 8, and in the Discussion Chapter, Chapter 9.

² See page 91 for a definition of this term.

CHAPTER 2

Methodology

What is the best method to study issues of identity, power and schizophrenia? Whilst a large quantitative study might present valuable data on such issues, this thesis proceeds from the assumption that a close, qualitative approach offers deeper, more detailed and more expressive material. As such, this thesis is based upon data drawn from the interpretive study of twelve people diagnosed with schizophrenia. Such a study, by its nature, offers depth rather than breadth of insight; highly individualised perspectives, rather than general “truths”. This focus on depth of understanding is reinforced by the researcher’s own status as a person diagnosed with schizophrenia; a point that will be explored below. Interviews themselves were semi-structured, allowing greater flexibility to draw out salient details of interviewees’ accounts, and focused on questions of identity disruption, rebuilding and maintenance.

Overview

Many researchers agree that there has been a paucity of studies of schizophrenia from the perspective of the person diagnosed (Scheper-Hughes and Lock, 1986, p. 137; Estroff, 1989, p. 191; Strauss, 1989, p. 179-181; Cook and Wright, 1995, p. 106; Markowitz, 1998, p. 344; Williams and Collins, 1999, p. 61; Chenoweth, 2000, p. 93; Gove, 2004, p. 372). As Estroff notes, [O]ur failure to identify and know the experiencing subject, their meanings, and the sense they make of schizophrenia represents a debilitating deficit in our understandings and responses via treatment (1989, p. 194).

This thesis hopes to address this lacuna by undertaking a detailed qualitative analysis of the personal, lived experience of people diagnosed with schizophrenia.

Perhaps the most important issue at this stage is to define the topic of the thesis in the form of a relatively clear research question. This question, in two parts, may be expressed as follows:

How do people diagnosed with schizophrenia maintain or re-establish their identity in the context of their illness, diagnosis and treatment, and how do relations of power inform this process?

In order to answer this question, the thesis reports on the results of a study involving in-depth, semi-structured interviews with twelve people who have been diagnosed with schizophrenia. The personal information of these people was supplied, after ethics submission, by the Australian Schizophrenia Research Bank administered by the Schizophrenia Research Institute. Questions addressed to the interview subjects sought to uncover a range of information, including factual history, such as the relevant case history of treatments and hospitalisation of participants. They sought to elicit information about how participants' identity (their self-image, self-esteem and self-construction) were affected by illness, diagnosis and subsequent treatment. Finally, they elicited information about how people rebuilt and maintained a sense of identity through specific processes such as limited disclosure and activities aimed towards the maintenance of self-image and self-esteem.

Qualitative Research

We may find an exemplary definition of qualitative research in Denzin and Lincoln (2005, p. 3; c.f.

Denzin, 2005, p. 10; Minichiello et al, 1995, p. 10):

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.

We may note certain features of this definition as significant, as they deal with issues that emerge throughout this chapter. The first such feature is the use of the word “situated”. This word refers to the belief amongst many qualitative researchers that their research is grounded in a certain moment and place – historically, politically, theoretically and academically. It is impossible to entirely remove the qualitative research act from its context and achieve an a-historical objectivity. The second feature is use of the phrase “make the world visible”. This phrase alludes to the belief that the “world” of research is not self-evident; the visible world is “created” in the act of research³. Finally the use of the phrase “transform the world” indicates that research contributes to actively changing the world, and part of that world is co-created by researcher and respondent through their research interaction (and myriad other interactions). With these characterisations of qualitative research, we must turn to the question of why the qualitative approach is suitable for the research task at hand.

Why engage in qualitative research rather than other approaches? For the simple reason that it offers the best opportunity for deep, meaningful and subtle engagement with the research question (Vidich and Lyman, 2000). At the heart of qualitative research is an interpretive act; an act of seeking to understand something meaningful about the social world; seeking what Weber described as “*verstehen*”, or “understanding”. Indeed, the attitudes – the “basic subject matter of nature and society” – of those diagnosed with schizophrenia are best understood with a sensitive, in-depth qualitative approach (Denzin and Lincoln, 2005, p. 12) that allows the researcher to achieve “rich descriptions”, or what Geertz describes as “thick description” (Geertz 1973, p. 5-6, 9-10) of the social world – with “careful attention to experience and phenomenology of self” (Estroff, 1989, p. 189; Cf. Burgess, 1984) – and which is compatible with the symbolic interactionist approach taken and described later in the thesis (Hammersley, 1989; Doubt, 1992).

³ C.f. Denzin and Lincoln, 2005, p. 19, for a description of the “triple crisis” facing qualitative research; in particular the “crisis of representation” where the researcher is faced with the difficult task of “directly [capturing] lived experience”.

The conceptual framework of this qualitative research may be said to be broadly interpretive. That is to say, the sociological research process is thought of as one of interpretation, where an academic artefact arises as the result of the process of grasping the meaning of, or interpreting, some part of social life (Neuman, 2000, p. 70-75). Hamilton describes such an approach as one “without pretensions to offer scientific knowledge or to claims of political significance” (2002, p. 27), and points to Goffman and Simmel as significant representatives of the interpretive tradition. The interpretive framework allows us a fair degree of latitude, both practical and aesthetic, in the analysis of interview data, and complements the qualitative, sociological approach. The thesis also borrows from a hermeneutic approach the emphasis on the “hermeneutic cycle”, where the interpreter must tack back and forth between specific parts of the research data and the project as a whole in order to come to a valid interpretation (Ezzy, 1998).

Research Design

The design of this research has involved twelve qualitative case studies – the semi-structured, in-depth interviewing of twelve people who have been diagnosed with schizophrenia – in order to gain a “deep” understanding of the processes of identity disruption, rebuilding and maintenance that occur in and around their experience and diagnosis of schizophrenia.

We may begin this part of the discussion with an attempt to define “case study”. Guba and Lincoln (1985, p. 360) state that there is little agreement over the definition of the case study. They refer to descriptions as simple as a “slice of life”, or a “depth examination of an instance”, to such rich statements as Denny’s (1978) “intensive or complete examination of a facet, an issue, or perhaps the events of a geographic setting over time”. We may adopt Denny’s definition, and elaborate upon it with Stake’s observation that the “case” in “case study” may be a “functioning body”, or a “bounded

system” (Flood as reported in Fals Borda, 1998) with “working parts and purposes”. For the research at hand, the case study is the “functioning body” of the individual interviewees, focused particularly on their experiences of schizophrenia.

The question may be asked: how useful is an in-depth study of limited numbers of people? At the first level, the case studies provide an opportunity for a “hermeneutic cycle” to be set up, tacking between the limited number of research subjects and the project as a whole. The further response must be that the research provides an in-depth insight into the rich individual experience of people with schizophrenia (Yin, 1989). This insight helps understand how a small number of people with schizophrenia and, by implication, others with the illness deal with identity disruption, rebuilding and maintenance in light of their illness. Indeed, the case studies provides both *intrinsic* interest and *instrumental* interest (Stake, 2005, p. 445); intrinsic insofar as issues involving the identity of people who have been diagnosed with schizophrenia are stimulating or interesting on their own from a broader sociological or academic point of view, and instrumental insofar as a better grasp of issues involved in the formation and maintenance of as sense of identity, as well as power relations, in people with mental illness may result from the study.

Research Sample

Research subjects have been drawn from respondents to a letter of request sent to the Australian Schizophrenia Research Bank (ASRB). The ASRB is:

“a national collaborative initiative designed to improve researcher access to data, samples, and volunteers to support schizophrenia research. The Bank [collects] clinical, genetic and brain image (MRI) data from people with schizophrenia and healthy controls. De-identified data/samples and potential research participants, are made available to Australian and international researchers” (Nectar, 2014).

After filing an Ethics submission for both the University of Sydney and the ASRB, a letter of invitation was sent from the ASRB to all research volunteers in NSW. The respondents then had their contact

details sent to the researcher, who arranged a time and a place to interview them. The research sample was of necessity small, as only a dozen people diagnosed with schizophrenia responded to the letter of invitation; it was beyond the powers of the researcher to choose specific subjects as samples. The names⁴ and ages of respondents at time of interview are noted here: Prescott, 37 years; Peter, 47 years; Greg, 44 years; James, 46 years; Nathan, 46 years; Ralph, 47 years; Michael, 34 years; Danielle, 40 years; Arthur, 62 years; Caitlin, 48 years; Gale, 49 years; and Sally, 61 years.

It is highly likely that only more stable and cogent sufferers responded, although this may have been an advantage given the thesis seeks information about people who have managed to re-establish some sense of stable identity after an experience of schizophrenia. The sample has been one of “convenience” drawn from ASRB. To a significant degree we may say that the respondents “self-selected”; that is to say, only a small “convenience” (Ezzy, 2005, p. 74) cross-section of people diagnosed with schizophrenia and members of the Research Bank decided to join the study. There is some precedent for the use of case studies in the mental health field (McGrew et al., 1999). Nevertheless, these parameters have, of necessity, limited the significance of research results, which makes no pretence to be comprehensive. Nonetheless, the task of giving voice to sufferers, no matter how limited, has been worthwhile, and the sample has fulfilled Minichiello et al.’ characterisation of “purposive cases”: cases that “represent specific types of a given phenomenon” (Minichiello et al, 1995, p. 13-14; Cf. Stenhouse, 1979).

Originally it was intended that both people diagnosed with schizophrenia as well as their carers or guardians would be interviewed. This could have provided a deeper insight into relevant issues and allowed interview responses by people diagnosed with schizophrenia to be cross-checked. However, this proved impractical for two reasons. Firstly, the majority of respondents lived on their own,

⁴ All names and identifying details have been changed.

without a carer or guardian. Secondly, a significant number of interviews saw the respondent come without carers into the city and participate in the interview in a safe space.

Data Collection Methods

The key data collection method adopted was that of the lengthy semi-structured interview, where the researcher brings an ordered list of questions to the interview, but retains the flexibility of asking follow-up or clarifying questions when and as they arise. This method allowed a deep and nuanced response to the thesis research question. The interviews sought information about the processes of identity disruption, formation and maintenance by people diagnosed with schizophrenia. The interviews also typically began with a brief discussion of the researcher's own status as a person diagnosed with schizophrenia in 2003. Interviews lasted approximately 1 hour.

The in-depth interview has a long history in social research (Merton and Kendall, 1946; Payne, 1951; Seidman, 1991; Schostak, 2006), and emerged especially as a tool for research in the Chicago School of Sociology. Guba and Lincoln (1985, p. 268) refer to interviewing as "conversation with a purpose". Fielding and Thomas define semi-structured interviews in contrast to structured interviews. They describe semi-structured interviews as "life history" and a "discursive format", where the interviewer may become actively involved in commenting on responses, putting interpretation to respondents and "sharing" their view with the respondent. Rosenblum (1987, p. 389) observes the contradictory nature of in-depth interviewing, where on the one hand the interview seeks to illustrate the deeply personal, whilst on the other hand also being an "impersonal, asymmetric, question-answer session" – both personal and impersonal.

Guba and Lincoln (1985, p. 268) identify various purposes for using interviews, the most relevant of which are "obtaining *here-and-now constructions* of persons, events, activities, organizations,

feelings, motivations, claims, concerns, and other entities”, “*reconstructions* of such entities as experienced in the past”, and “verification, emendation, and extensions of information... obtained from other sources, human and non-human”. Let us delve a little more deeply into the benefit of semi-structured interviewing, or “open questions”. The open question interview has a rich history, including advocates of open questions such as sociologists Max Weber and William Thomas, and ethnographical anthropologists such as Harold Garfinkel, Aaron Cicourel, Jack Douglas and Charles Briggs (See Foddy, 1993, p. 126). All these social scientists have emphasised that the acts of people must be understood in terms of the meanings those people attribute to the acts.

Foddy (1993, p. 128) points out further benefits of semi-structured interviews, the most relevant of which are that they allow respondents to express themselves in their own words, do not suggest answers, avoid format effects and (perhaps most importantly) allow complex motivational influences and frames of reference to be identified. Lazarsfeld (1944) likewise argues that open questions are useful for clarifying the meaning of respondents' answers, discerning influences on opinions (for example, the dimensions of the topic and personal motivations that have influenced respondents), and clarifying the nature of the relationship between variables. Research by Belli et al. (2001) suggests the benefit of “event history” interviews over question list surveys for the recollection of life events. From the position of reality as language, Denzin (1992, p. 90) goes on to argue that qualitative research inevitably calls forward stories, narratives and “self texts”, such as biographies and autobiographies (Cf. Riessman, 1993; Riessman, 2008). The importance of story in interview dialogue is emphasised by Atkinson (2007, p. 224) – “We think in story form, speak in story form, and bring meaning to our lives through story. Our life stories connect us to our roots, give us direction, validate our own experience, and restore value to our lives”.

The benefits of semi-structured interviews must not be lost in this discussion. Such interviews have allowed greater access to the complex and meaningful thoughts, attitudes and experiences of

research subjects through an engagement with meaningful self-stories (Minichiello et al, 1995, p. 85; C.f. Askham, 1982). Indeed, the interviewer sought the respondent's personal stories.

Interviews themselves were initiated with a short period of conversation to help establish rapport (Walter, 2006, p. 97). At this point the researcher described his own position as a person diagnosed with schizophrenia. This self-description typically helped establish trust and affinity with interviewees; a sense, perhaps, that the interviewer had a personal insight into experiences interviewees were to re-tell. The interviews were then structured through the model of "funnelling", starting out with questions of a general factual nature, moving towards more specific questions about the issues at hand (See Minichiello et al, 1995, p. 84; c.f. Foddy, 1993, p. 61). The interviews have also followed the principles of question design outlined by Sudman and Bradburn (1982, p. 13; quoted in Foddy, 1993, p. 32) of not formulating specific questions until the research question has been thought through, and even going so far as to write the research question down and keeping it handy to formulate specific questions. Questions were also written so as to avoid words with unclear or multiple meanings; especially such words as "regularly", "frequently", "good", "approve" and "dislike" (Foddy, 1993, p. 43)". When posing questions seeking to uncover material for life history, the interviewer used targeted inquiries about specific events and stimuli (Foddy, 1993, p. 58). We may extend on the point made here to emphasise that the use of questions regarding sensory perceptions may stand out in people's memories (Mitchell, 2007). At the same time, questions regarding embarrassing events (such as accepting one has mental illness) had their own distinct structure, using an open format and the respondent's own words (Foddy, 1993, p. 114; C.f. Blair et al, (1977). The design of the semi-structured interview questions also bore the imprint of the interviewer as a person diagnosed with schizophrenia. Important elements of his own experience suggested possible avenues of questioning.

From this point, broader questions about key issues of the thesis were asked. For example, issues of social support and illness management that were not considered in the original question brief tended to emerge as the interviews progressed and analytic themes developed. Indeed, the development of new themes during the process of interviewing posed a challenge to the structured elements of the interview; as time wore on, the semi-structured elements of interviews, involving emergent themes, tended to predominate. Throughout the process, the interviewer sought to account reflexively for his own prejudices, values and social position.

At this point it is apposite to consider some of the methodological issues addressed earlier in this chapter; those raised by the postmodern or poststructural turns in qualitative research (Lather, 1993; Richardson 1991). Denzin (1992, p. 84) observes that self-stories are inherently told in an experiential context, especially personal narratives. Fontana and Frey (2005, p. 695-696) argue that interviewing is:

inextricably historically, politically, and contextually bound. This boundedness refutes the whole tradition of the interview of gathering objective data to be used neutrally for scientific purpose... As many have argued convincingly (Atkinson and Silverman, 1997; Fontana, 2002; Hertz, 1997; Holstein and Gubrium, 1995; Scheurich, 1995), interviewing is not merely the neutral exchange of asking questions and getting answers. Two (or more) people are involved in this process, and their exchanges lead to the creation of a collaborative effort called *the interview*. The key here is the "active" nature of the process (Holstein and Gubrium 1995) that leads to a contextually bound and mutually created story – the interview.

The upshot of these issues would seem to be that we must, in this research, consider meaning as a co-created process; albeit one in which we may take a reflexive attitude (see Fook, 1999) to the political, social and academic context in which the research takes place.

Data Analysis And Synthesis

Data from the semi-structured interview were analysed and synthesised in this (nominal) step in the research process. Analysis proceeded by close reading, looking for emergent themes and gradually coding these themes.

As discussed, the research method was aided by the researcher's status as a "consumer researcher"; a person diagnosed with schizophrenia. This status allowed a particular insight into the answers given to questions posed to interviewees. In particular, experiences of symptoms, diagnosis, hospitalisation and medication were often shared, to some extent, by the researcher. The impact of stigma and difficulties "going public" about the illness were also provided by this status. Beyond this personal insight, a number of strategies were followed in data analysis and synthesis. In particular, the researcher focused on engaging in what has been described as a "hermeneutic circle" (Gadamer, 1988; 1989); a movement between specific lines of interviewee's dialogue and the interview as a whole. The researcher became thoroughly familiar with the data prior to and during analysis (Fielding and Thomas, 2001, p. 137). Specific lines, sentences and paragraphs were marked as meaningful and, as they accumulated, convergences and dissonances were noted (Ezzy, 2002, p. 94). Analysis proceeded via free association, making comparisons, the research map, shifting focus, shifting sequence, the interrogative list, the substantive checklist, and transposing data (Minichiello 1995, p. 256). Assertions and thematic expressions were emphasised (Atkins, 1984, p. 256); common themes were identified to link issues emerging from the respondent's expression (Minichiello, 1995, p. 248). The process involved the creation of an informal coding system to reorganise data according to conceptual themes (Minichiello, 1995, p. 255-257). As noted, certain analytical and theoretical observations emerged during the process of interviewing (Ezzy, 2002, pp. 61-62; Kvale, 2007; c.f. White and Drew, 2011, p. 7; Glaser and Strauss, 1967; Pelias, 2004) and writing (Richardson and St. Pierre, 2005). Throughout the analytic process, the researcher engaged reflexively with his own position and tradition, and fused these with the meaning and context of the interviews. Indeed, pre-conceptions regarding patients with mental illness as well as contextual factors such as academia, the nature of the PhD and the formalities of study were acknowledged.

A number of problematic issues emerged during the data analysis. Most importantly there developed an issue around whether cases of dual diagnosis (typically of a mental illness and a substance abuse problem) provided strong data for analysis. It was unclear, for example, whether an emotional state spoken of had arisen as a result of the schizophrenic experience, or from the substance abuse problem. A similar problem emerged with cases of severe paranoia. Finally, the issue of family violence arose; in particular, whether such violence was caused by or exaggerated by a psychotic state. In each of these cases, the researcher had to be careful in interpreting interview information that may have been informed by the respondent's particular experience of the world.

Writing Up

Having successfully gathered, analysed and coded the data for this research, the findings were written up in Chapters 6, 7 and 8. It was necessary that the writing be at once clear, concise and expressive while at the same time doing justice to the "thick description" of the processes of identity change and maintenance amongst people diagnosed with schizophrenia.

This was a process where patience was valuable (Bauman, 2000, p. 85) and where clarity and simplicity were beneficial (Mills, 1959, p. 239; Richardson 1990). In the complex process of writing up, it was also unavoidable that details were omitted; it was best that such decisions to omit were made with respect to the central theme of current research (Ezzy, 2002, p. 139). Nevertheless it was important to include "a mixture of theoretical analysis and illustrative extracts from the primary data" (Ezzy 2002, p. 146-147). The researcher quoted extensively from segments of interview texts in the final study to aid the expression of key ideas and themes, interweaving viewpoints and perspectives (Guba and Lincoln, 2005, p. 197).

Issues Of Validity And Reliability

There are writers who emphasise validity and reliability in qualitative social research. For example, Minichiello (1995, p. 176-177) argues that in-depth interviewing attempts to “stay close to the empirical world” to ensure a “close fit” between the data gathered and the acts and beliefs of subjects. According to Taylor and Bogdan (1984), this can be accomplished by calling things by the right names or being concerned with the correctness of one’s understanding of the informant’s perceptions, view, attitudes and behaviours. Furthermore, the researcher engaged in testing perception and understanding against sources of error to draw tentative conclusions, and used probing, cross-checking and recursive interviewing to check the validity of data (Kirk and Miller 1986). However, qualitative research and, especially, in-depth interviewing creates a product derived from the mind of both interviewer and interviewee, where there will always be questions about the accuracy involved in “capturing” someone’s thoughts (Link, 1943, p. 269). Reliability is achieved through testing the strength of data; however it has been observed that while qualitative research may provide valid understandings of informants’ intended meaning, its flaw lies in the difficulty of replicating research, making it difficult to assess reliability (Sandelowski, 1986). Indeed, the nature of interpretive sociology suggests that the result of research will be singular; limited by the position and interests of researcher and subject. Other issues of reliability and validity in the particular genre of the interview have been raised (eg. Lazarsfield, 1944; Dohrenwend, 1965; Schuman and Presser, 1979; Converse and Presser, 1986; Schwarz and Hippler, 1987; Fowler and Mangione, 1990).

With these thoughts in mind, we cannot apply the natural science’s model of validity and reliability to the study at hand. There are a number of problems with such an approach, as Ezzy (2002, p. 53-54) points out:

It is relatively easy to deconstruct the natural sciences model of qualitative research by demonstrating the problems associated with applying natural sciences methods to the social world. It is much harder

to construct an alternative. If the old model does not make sense any more, what can be used instead as a criteria for assessing the rigour, quality and trustworthiness of research?... [T]here are [models of research] that focus on the interpretative process... These models emphasise obtaining of high-quality description through a sensitivity to the complexity of meanings, feelings and interpretations of participants and researchers. This model tends to reject the correspondence model of truth that emphasises the role of validity and reliability. In qualitative research, “the key problem is understanding how individuals interpret events and experiences, rather than assessing whether or not their interpretations correspond to or mirror the researchers’ interpretive construct of “objective” reality.

The remainder of this section will be given over to considering Guba and Lincoln’s (1985) proposed criteria for acceptable qualitative social research⁵. Guba and Lincoln (1985, p. 300) attempt to offer a qualitative counterpart for each quantitative criteria (being internal validity, external validity, reliability and objectivity):

- Credibility
- Transferability
- Dependability
- Confirmability

In the present study, credibility was ensured by the depth of analysis – a “thick description” (Geertz 1973, p. 5-6, 9-10) embracing complexity and subjectivity. The quality of scepticism was also important to credibility, with a self-conscious approach to social, political and academic context, and a reflexive approach to the researcher’s own position as a mid-30s white heterosexual male, of comfortable means, engaging in pure academic research with people who are often marginalised in wider society (see Fook, 1999 for a discussion of the importance of reflexivity in social research). Finally, the use of “negative case analysis” (Guba and Lincoln, 1985, p. 309) to ensure subtlety and nuance of research findings was engaged. Transferability was ensured by the consideration of similar research. Dependability relied on the rigour of repeated semi-structured interviews. Finally, the quality of confirmability was sought through cross-reference in the (admittedly small) sample size, and through peer review of thesis findings and analysis.

⁵ See for a discussion of qualitative versus quantitative criteria for rigour Margarete, 1986. See for alternative conceptions of acceptable qualitative research Ezzy, 2002; Holstein and Gubrium, 1995; Charmaz, 2005.

Limitations

There are a number of limitations to this study that must be acknowledged. Theoretical challenges to the project are considered elsewhere in this chapter; this section shall focus on more practical issues (recognising that practical and theoretical problems may overlap).

Perhaps the most significant limitation to the project was the relatively small number of people who were involved as participants. This small “convenience” sample limited the ability to generalise from findings (Hamilston, 1980; Guba and Lincoln, 1985; Ezzy, 2002, p. 74; Walters, 2006, p. 103), although the task of the project is to find deep, rather than broad information. Indeed, the significance of the thesis rests on the premise that small samples in interview-based qualitative research may provide material that is more detailed and comprehensive about particular experiences or issues than a broader qualitative or quantitative study (Crouch and McKenzie, 2006).

A second limitation lay in the memories of participants. The data provided by participants was essentially retrospective, and may have been slanted, incomplete or narrativised because of this. Sufferers may have been in an unstable mental state at times of crucial interest for the project, and may have taken and continue to take medication affecting the detail and depth of memories. The problem of memory may have been further complicated by the observations that respondents' “attitudes, beliefs, opinions, habits, interests often seem to be extraordinarily unstable” (Foddy, 1993, p. 4). In response to the problem of memory the researcher undertook a number of tasks, including probing more deeply where respondents offered inconsistent information or, where that inconsistency remained, to disregard data. Efforts were taken to cross-check information at different points of the thesis. Foddy's observations regarding memory (1993, p. 93; c.f. Sudman and Bradburn, 1982, p. 42-47) were kept in mind, namely that the salience of experiences makes them easier to

remember, especially when the memory is unusual, involves high costs or rewards, and continuing consequences. Furthermore, the structured part of the interviews were designed with the observation that memory may be “transformed in storage” and become arranged around “concepts such as pain, incapacity, costs, visits to doctors, hospitalisation, medication or treatment, symptoms or more generally around other causal, circumstantial or consequential events” (Foddy, 1993, p. 97; referring to Cannell (1977, p. 55)).

Some participants were hesitant about volunteering closely held personal information about a condition that involves compromised status and identity. For example, in one case, discomfort with questioning caused a respondent to terminate the interview early. The response to such situations was to attempt to gain the trust of respondents. This was attempted through emphasising the researcher’s own status as a person diagnosed with schizophrenia, as well as a respectful and interested personal manner, and through the staggering of general to more personal questions. The researcher attempted to avoid the twin traps of under-identification and over-identification with the research respondents (Guba and Lincoln, 1985, p. 177).

Respondents may have also succumbed to the “social desirability effect”, “where interviewees slant what they reveal about themselves to give one impression or another” (Walter, 2006, p. 103). This effect was countered by a close focus on respondent’s comments, especially contradictions or areas of greater sensitivity.

Ethical Considerations

The key ethical considerations in this research revolve around the consent and treatment of respondents diagnosed with schizophrenia.

Schizophrenia is not only a debilitating disease, it is also in almost all situations an unwanted part of the sufferer's identity. Sufferers may feel very uncomfortable discussing their illness, and may take specific precautions so that their illness is not revealed in social situations. In light of this situation, a number of precautions were taken when dealing with potential interview subjects. Many of these are detailed by Minichiello (1995, p. 206) and Christians (2005).

Perhaps the most important ethical precaution is to ensure the fully informed consent of respondents, and their full privacy and confidentiality. Informed consent was ensured by including for the participants, an accurate account of aims and processes of the project. This account gave a candid picture of what questions were to be asked, what issues arose and the goals of the project. Potential participants had freedom to give or withhold consent. Furthermore, participants were informed in writing that they were free to answer or not answer any question; that they may request certain information given not to be used in the research; and that they may terminate the research relationship at any time. Such measures became significant in one case, where a respondent was asked to give a second interview to elaborate on emerging themes, but decided not to do so.

Participants were also informed, and appropriate actions were taken, in order to limit access to respondents' interview transcripts, tapes and analysis to the researcher and his supervisors. Information that may have identified individuals – names and recognisable personal characteristics – were changed or omitted. Research was also undertaken with a strict intention to “do justice” to the data given in interviews; where thick description was an important goal. The quality of trust between the researcher and respondents was sought and valued (Cheek, 2005, p. 401; 1985, p. 282). Finally, it is important to acknowledge that the recognition of respondents' special and/or compromised status may be a significant ethical consideration; especially as “Nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false,

distorted, and reduced mode of being. Due recognition is not just a courtesy we owe people. It is a vital human need” (Taylor et al, 1994, p. 26).

This thesis seeks to recognise a group of people who are too often on society’s fringes. Indeed, the thesis fundamentally aims to bring the subjective experiences of these people to light, avoiding the “reduced mode of being” that people stigmatised by schizophrenia may experience.

CHAPTER 3

Theoretical Perspectives: Stigma, Identity and Social Interaction

How can the tools of sociology help us understand the relationship between illness, identity and schizophrenia? Perhaps the best place to begin is with Erving Goffman's sociology of stigma, which seeks to understand how people with discredited or unwanted identities, such as suffering a mental illness, must "conceal" their stigma or "pass for normal", and often divide their social world into those who know and don't know about their condition. Whilst rich in detail and nuance, however, Goffman's work does not provide a general theory of identity. This thesis finds such a theory in Symbolic Interactionism, which offers a wider account of the nature of identity, of identity formation and of identity maintenance. Indeed, Chapters 3, 4 and 5 can be understood as a critical presentation of both the symbolic interactionist perspective as well as some theory from outside symbolic interactionism that may complement the perspective. The symbolic interactionist emphasis on identity as "process", meaning generated through interaction, and the importance of absorbing the perspective of the general other are all significant and useful insights. These insights provide a useful framework for analysing the specific process whereby a sense of identity is disrupted, rebuilt and maintained in people diagnosed with schizophrenia. Finally, the area of applied interactionism dealing with "reconstructing identities" – in particular, the literature regarding "illness narratives" – helps give insight into how people with schizophrenia deal with the disruption of their condition, and provides tools to unpack the interviews given by respondents. In what follows, I will look at each of these perspectives in detail, taking care to note the ways in which they might illuminate (or indeed fail to illuminate) the research study at hand.

Goffman and Stigma

This section focuses on the work of Erving Goffman to illustrate a fundamental process affecting identity – stigma. Although Goffman’s work on this topic occurred after much of the material regarding symbolic interactionism was released (indeed, symbolic interactionism influenced Goffman deeply), it will better suit the unfolding terrain of theory in this thesis to consider Goffman first. We may start by acknowledging that self-presentation of a stigmatised sense of identity is a vital part of identity maintenance. We consider here Erving Goffman’s work (1963) *Stigma: Notes on the Management of Spoiled Identity*⁶ and, to a lesser extent, his work (1959) *The Presentation of Self in Everyday Life*. The first work explores how people with identities or conditions such as mental illness that are considered deviant, or “stigmatised”, manage their interactions with non-stigmatised people in order to protect their self and reputation – that is to say, how they engage in a process of identity maintenance. The book includes as “stigmatised” conditions homosexuality, criminality, mental patienthood, teenage delinquency – obviously mental patienthood is most relevant, although it is interesting that Goffman identifies common self-management techniques for people with different stigmatised identities (Goffman, 1963, p. 32).

Stigma arises through the reaction of broader society to a condition the stigmatised person may have. “By definition... we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances” (Goffman, 1963, p. 5). Stigma is itself defined pithily: “The term stigma... will be used to refer to an attribute that is deeply discrediting” (Goffman, 1963, p. 3). Clearly schizophrenia is a stigmatised condition, and the diagnosis of schizophrenia a violent introduction into this

⁶ Similar techniques and accounts of stigma have also been described elsewhere (see, eg, Page, 1977, Rabkin, 1980. 1983; Crocker, 1989; Hylar et al., 1991; Monohan, 1992; Socall, and Holtgraves, 1992; Hayward and Bright, 1997; Jorm et al., 1997; Link et al., 1997; Rosenfield, 1997; Holmes and River, 1998; Wahl, 1999; Link and Phelan, 2001; Crocker and Park, 2003; Kelly and Jorm, 2007; Perkins et al., 2009).

stigmatised condition (Cf. for discussion of stigma Crocker et al., 1998; Farina, A. 1998; Farina et al., 1973; for discussion of severe mental illness and stigma see Corrigan, 1998, 2004; Corrigan et al., 2000; Corrigan et al., 2002; Corrigan et al. 2006). Indeed, schizophrenia is frequently understood by members of the public as referring to dissociative personality disorder (“multiple personalities”) and as having a strong relationship to the propensity for violence (Grohol, 2016; House With No Steps, 2016; SANE 2016).

Early in his text, Goffman quotes R. Barker ⁷ on the impact a stigmatised identity can have on a normal person:

The awareness of inferiority means that one is unable to keep out of consciousness the formulation of some chronic feeling of the worst sort of insecurity, and this means that one suffers anxiety and perhaps even something worse, if jealousy is really worse than anxiety.

Goffman also recognises that stigma can “spread” to those in close relationship to the stigmatized:

[T]he tendency for a stigma to spread from the stigmatized individual to his close connections provides a reason why such relations tend either to be avoided or to be terminated (1963, p. 30).

The bulk of Goffman’s text, however, is constituted by an analysis of the management of the stigmatized condition through various social techniques, typically limiting wider knowledge of the stigmatized person’s condition (1963, p. 21). Thus “[t]he very anticipation of... [social] contacts can of course lead normals and the stigmatized to arrange life to avoid them” (1963, p. 12). And further: “during mixed contacts, the stigmatized individual is likely to feel that he is “on’, having to be self-conscious and calculating about the impression he is making, to a degree and in areas of conduct which he assumes others are not” (1963, p. 14). Being “self-conscious and calculating” about the impression one is making – this form of “management” – is a good example of identity maintenance. This approach echoes the concept of “impression management” discussed in Goffman (1959, p. 208) as a vital element of the self in social interaction. Such management takes place in a number of ways. In an essay entitled “Information Control and Personal Identity”, Goffman discusses a number

⁷ 1956, H. Perry, M. Gawel and M. Gibbon (eds.) *Clinical Studies in Psychiatry*, New York: W. H. Norton and Company, p. 45.

of techniques, including “passing” and “concealing stigma symbols”. The overall approach is titled “stigma management” (1963, p. 51) and will become relevant to the research of identity maintenance in this thesis.

Goffman observes that “[t]he first set of sympathetic others is of course those who share [the] stigma” (Goffman, 1986, p. 20). Goffman further comments that people with stigma may seek out others sharing the said stigma; perhaps by joining clubs or support groups. Such behaviour is seen in the person with schizophrenia seeking out groups of people that share schizophrenia; as we will see, a number of research interviewees spend time at an institution for those with mental illness called the Leisure Club. However, the stigmatised person cannot control his or her circumstances at all times, and must either retreat into isolation or confront dealing with members of the public. Here, Goffman emphasises “visibility” of the stigma. In *The Presentation of Self*, Goffman refers to the unwanted visibility of such hidden conditions as “discrepancy” in social presentation, or “performance disruption” (p. 212). It may be noted here that schizophrenia is not a strictly visible illness; however, symptoms and drug side-effects such as tremors, flat affect and misreading social cues can soon become visible. In this case, the stigmatised person will make a division between “the knowing” who know of his or her stigmatised status, and the “unknowing”. Often a stigmatised person will handle the risks of his or her stigma by “dividing the world into a large group to whom he tells nothing, and a small group to whom he tells all and upon whose help he relies” (Goffman, 1986, p. 95). When confronted with the large group of the unknowing, techniques of identity management include “passing” for normal by hiding one’s stigmatised condition. Such a technique may be easier when the stigma is not clearly visible, as is sometimes the case with schizophrenia. A mental patient may attempt the “concealment of stigma symbols” by compensating for such symptoms and drug side-effects as flattened affect, tremors, inability to perceive emotional cues and paranoia, as we shall see in Chapter 8. Such passing or compensation may be understood as a form of what Goffman (1953) calls “impression management” – the dramatised presentation of a socially acceptable self in

social interaction. In many situations the stigmatised person may need to participate in society in a way that feels inauthentic or difficult in order to present a socially acceptable self (Goffman, 1986, p. 121). Goffman also describes the work a stigmatized person may do to hide his or her stigma:

The stigmatized individual can... attempt to correct his condition indirectly by devoting much private effort to the mastery of areas of activity ordinarily felt to be closed on incidental and physical grounds to one with his shortcoming (1963, p. 10).

Thus a person with schizophrenia may attempt through psychological training to better perceive emotional cues. Furthermore:

The phenomenon of passing has always raised issues regarding the psychic state of the passer... [I]t is assumed that he must pay a great psychological price, a very high level of anxiety, in living a life that can be collapsed at any moment (1963, p. 87).

Goffman's discussions of stigma management techniques can offer us an insight into the personal state of mental patients, as well as the use of such techniques to hide their diagnosis and maintain their "normal" identity. Furthermore, we may borrow from Goffman an emphasis on pathological processes of the self that may be deficient in earlier work in symbolic interactionism, as we shall see below. Goffman also provides a dramaturgical reading of the self – self as "presentation" or "performance" – that may help us understand the ways people with schizophrenia maintain their identities through performance with other people. Finally, the various activities a person may engage in to hide their pathological state offer a clear example of identity maintenance.

What are the limitations of Goffman's work? Goffman's work can be criticised for offering an external account of identity formation – the stigmatised identity is imposed from the outside.

Although stigmatised subjects may practice passing or concealment of stigma symbols, they do not necessarily internalise this view of their identity and, if they do, we do not learn from Goffman how this might take place. We are left with the external performance, whilst internal experiences and compulsion are neglected. Furthermore, Goffman's work does not explore the macro features of society that provide the context for individual relations of stigma. Although this problem is addressed to some extent in his work *Asylums* (1961), the deinstitutionalisation movement (which is

addressed below) has reduced the power of asylums, clinics and hospitals to impose binding identities on patients.

Symbolic Interactionism

Some of the limitations we find in Goffman's work are addressed by the model of symbolic interaction developed by (inter alia) George Mead and Herbert Blumer.

Symbolic interactionism encompasses a range of approaches that emphasise meaningful interaction between social agents as the source of such phenomena as the mind, meaning and, significantly, the self. It also offers a wider approach to questions of identity than presented by Goffman; in particular, proposing a view of the internal self communicating with an external world and allowing for the process of people internalising identity.

Symbolic interactionism draws heavily on the work of George Herbert Mead. This section presents his analysis of the creation of self. Before doing so, however, we should acknowledge Doubt's analysis of the relationship between Mead's theory of the self and the breakdown of self in schizophrenia:

What... is the situation with schizophrenia? What is painful about watching schizophrenics struggle with their illness is that we watch how the illness constitutes a serious invasion of the self. What is uniquely tragic about schizophrenia is that it directly confronts the character of the human self and so the ability of the human self to be itself (Doubt, 1992, p. 310).

We should also recognise that symbolic interactionism may move some way towards engaging with the personal narratives of people suffering schizophrenia. At this point we may begin the analysis of Mead's work. This analysis begins with an account of "meaning". Mead argues that when one person attempts to communicate with another – when they attempt to express meaning – that person actually considers the impact of the expressed term within him or herself. Thus Mead states:

The gesture is that phase of the individual act to which adjustment takes place on the part of other individuals in the social process of behavior. The vocal gesture becomes a significant symbol... when it has the same effect on the individual making it that it has on the individual to whom it is addressed or who explicitly responds to it, and thus involves a reference to the self of the individual making it. (1967, p. 46).

It is important to clarify the point being made here. For Mead, the meaning of a term is that which gives rise to a response *both* in the person making the meaningful statement and the person receiving the statement during an interaction involving significant symbols. The process is intrinsically social. This is also true of the development of the self: “The self... is essentially a social structure, and it arises in social experience... it is impossible to conceive of a self arising outside of social experience” (Mead, 1967, p. 140) or put differently: “When we reach a self we reach a certain sort of conduct, a certain type of social process which involves the interaction of different individuals and yet implies individuals engaged in some sort of cooperative activity. In that process a self, as such, can arise” (Mead, 1967, p. 165). It is important to note that this social process is just that – a *process*, rather than an end-point in personal development: “The self is not so much a substance as a process” (Mead, 1967, p. 178).

Mead offers an account of how the structure of the self is developed and realised through social interaction – “[it] develops in the given individual as a result of his relations to [the process of social experience and activity] as a whole and to other individuals within that process” (Mead, 1967, p. 135). The essence of achieving self-hood is for a person to experience his or herself as an object through the eyes of another person (C.f. Tice and Wallace, 2003). The self, as the heart of human subjectivity and the result of identity formation, requires external perception in order to develop. The person thus becomes an object to itself, seeing itself through “individual members of the same social group, or from the generalized standpoint of the social group to which he belongs” (Mead, 1967, p. 138; Stets and Burke, 2003; although see Tice and Wallace, 2003, p. 94-97 for criticism of this position). “The organized community or social group which gives to the individual his unity of

self may be called the 'generalized other'. The attitude of the generalized other is the attitude of the whole community" (Mead, 1967, p. 154). Furthermore:

[O]nly in so far as he takes the attitudes of the organized social group to which he belongs toward the organized, co-operative social activity... in which that group as such is engaged, does he develop a complete self (Mead, 1967, p. 155).

This point is vital to the task at hand as it outlines a process against which we may judge the degree to which respondents have recovered from the biographical disruption of schizophrenia; indeed, it might be the failure to see oneself from the perspective of the other which is itself at risk or lacking in the schizophrenic experience, as we see in the Chapter 6. An argument along these lines is made by Rosenberg (1984, 1992). Rosenberg draws upon symbolic interactionism, and the work of Mead (amongst others), to contend that "insanity" is defined by a failure in the ability to role-take during social interaction. More will be said below of Rosenberg's work. In a similar vein to Rosenberg, the following quote makes the point that "taking the attitude of the other" is vital to experiencing oneself *as a self*:

When the response of the other becomes an essential part in the experience or conduct of the individual; when taking the attitude of the other becomes an essential part in his behaviour – then the individual appears in his own experience as a self, and until this happens he does not appear as a self (Mead, 1967, p. 195).

Taking the attitude of the other inevitably involves the person with the rules and structures of his or her community; in some sense, the communal life is prior to the individual self (Mead 1967, p. 162), although Mead does recognise that people can change, that each self has "its own peculiar individuality" (Mead, 1967, p. 201) and people can effect change in their communities. It is also important to note that this "becoming an object to itself" takes place through the medium of language: "...the language process is essential for the development of the self" (Mead, 1967, p. 135).

This point is explored further in Chapter 9. People suffering schizophrenia who speak confused language – "word salad" – may fail to achieve a successful self for this reason⁸. Although none of the

⁸ On the topic of confused expression by people with schizophrenia, it has been argued that such language can in fact be understood using Kenneth Burke's distinction between "semantic" and "poetic" meaning. Indeed, Doubt argues (1994) that such language can typically be seen as a miscomprehension of semantic language; a person with schizophrenia may respond to communication with an overly semantic interpretation of poetic

respondents interviewed suffered from such confused language, the fact of its existence reinforces the threat schizophrenia can pose to the self. Likewise, as Doubt points out, the person diagnosed with schizophrenia may not be able to take the role of the other:

In taking the role of the other, we are controlled by society, but, more importantly, we control our relation to society as well as society's relation to us. Insofar as schizophrenics seem unable to take the role of the other, whether due to their illness or to others' view of them, it becomes difficult for them to control their relation to society as well as society's relation to them (Doubt, 1992, p. 313).

Nevertheless, despite this difficulty, Doubt emphasizes that, to understand the identity of the person with schizophrenia, it is necessary to recognize how people with schizophrenia do engage in role-taking, calling it role-taking success.

Mead also traces the development of the social self in children. He emphasises two aspects of development: "play" and "game". In the play period, the child is presented with a particular set of stimuli aligned with a common social role. The child learns to respond to these stimuli correctly, building a social self; the child "utilizes his own responses to ... stimuli which he makes use of in building a self" (Mead, 1967, p. 150). The game is somewhat more sophisticated. It involves a set of rules governing interaction that are agreed upon, usually tacitly, by others in the game. The developing child must be able to understand the game and its rules from the perspective of the other children, and must be willing to take any role in the game taken by any other person.

Interestingly, Mead acknowledges that there may be different parts of the self that emerge in different circumstances:

[A] good deal of the self does not need to get expression. We carry on a whole series of different relationships to different people. We are one thing to one man and another thing to another. There are parts of the self which exist only for the self in relationship to itself (Mead, 1967, p. 142).

This is a view that dovetails nicely with Goffman's concept of the dramaturgical self. Mead's picture of different selves being presented to different people helps us to understand the diverse situations

language, or an overly poetic interpretation of semantic language, giving rise to apparently non-sensical expression. Cf. Doubt (1996).

of respondents in Chapter 6, 7 and 8 (Mead, 1967, p. 142; C.f. Shlenker, 2003, for a perspective on social behaviour as a “performance”; Joas, 1987). Indeed, this multiplicity of the self may help explain the particular self-experiences of people diagnosed with schizophrenia, although there are some limits to Mead’s approach, as explored below.

One of the more complicated elements of Mead’s approach to the self is his definition and distinction between the “I” and the “Me”. The “I” is the response of the person to the attitudes of others, whilst the “me” is the set of attitudes of others that the person assumes. “The attitudes of the others constitute the organised “me’, and then one reacts that as an “I”” (Mead, 1967, p. 175). To rephrase, the “me” is the repository of socialisation, the absorber of social attitudes, whilst the “I” is the active agent that acts upon the basis of information from the “me”. Here we can see that Mead offers a much more nuanced account of the self than we find in Goffman’s theory of stigma: the “me” is “the set of attitudes of others” but it is also assumed by the person and is thus never a mere imposition while the “I” emerges when the person actively responds to the attitudes of others.

Mead elaborates:

The “me” and the “I” lie in the process of thinking and they indicate the give-and-take, which characterizes it. There would not be an “I” in the sense in which we use that term if there were not a “me”; there would not be a “me” without a response in the form of the “I”. These two as they appear in our experience, constitute the personality. We are individuals born into a certain nationality, located at a certain spot geographically, with such and such family relations, and such and such political relations. All of these represent a certain situation, which constitutes the “me”; but this necessarily involves a continued action of the organism toward the “me” in the process within which that lies. The self is not something that exists first and then enters into relationship with others, but it is, so to speak, an eddy in the social current and so still a part of the current (Mead, 1967, p. 182).

Furthermore, “The “I” reacts to the self which arises through the taking of the attitude of others. Through taking those attitudes we have introduced the “me” and we react to it as an “I”” (Mead, 1967, p. 174). It is possible to use the “I”/“me” distinction as a means to account for emotional experience in the self – that is to say, we may see the “I” as the emotional or affective side of the self, and the “me” as the cognitive side. However, such a contention is not strongly thematised by

Mead and it is arguable that we need to move beyond Mead to find a more comprehensive way of understanding emotional or affective self-experiences, including in schizophrenia.

The last sentence in the quote above is also interesting. Mead compares the self to an “eddy” swept along by the superior force of the “social current”. Perhaps we may regard the diagnostic process and hospitalisation as an eddy in the social current of the diagnosed person’s life. However, this comparison is somewhat deterministic; a limitation that is considered below, but one which is recognised by Mead in his analysis of the relation between self and society (Mead, 1967, p. 192).

Mead offers a strong theoretical and philosophical position from which we can attempt the analysis of rebuilding a sense of identity after the diagnosis of schizophrenia. Using Mead’s insights we can suggest that rebuilding identity is an intrinsically symbolic process, involving symbolic interchange of gestures and a deep engagement with the external views of individual people or the “generalised other”.

However, there are a number of aspects of his work that are under-theorised, or to which Mead does not advert, that limit the usefulness of his thesis as a basis for the study at hand. Mead offers a picture of identity forming in an essentially healthy and normal manner. He does not discuss the emergence of “pathological” self-states such as schizophrenia, nor the possibility that deviant groups or subcultures may emerge within society. Mead is unclear on the relationship between self and society; that is to say, he does not state to what extent self affects society and society affects self and, through this, identity formation. Mead’s position may also encounter difficulties in making sense of all experiences of schizophrenia; for example, Mead’s generally ideational position may falter when faced with emotional or embodied experiences of schizophrenia (accepting the criticism made here of using the “I”/“me” distinction as a way to include the emotional or affective in Mead’s schema). This point is analysed further in Chapter 9. As has been noted, Mead’s picture of macro-

society, and his discussion of the synthesis between micro-analysis and macro-analysis, is also incomplete; to some extent, this issue is dealt with under the section on Diagnosis, Power and Identity below. Linked to this issue, and an issue in itself, is how questions of power and hierarchical social structure affects the self-creation procedure. Certainly the issue of the psychiatrist's position in the psychiatric apparatus plays a significant role in the understanding and acceptance of schizophrenia, and is considered, among other issues of power, below.

Many of these issues are considered in the later work of Herbert Blumer on symbolic interaction. In his most well-known work, *Symbolic Interaction: Perspective and Method* (1986), Herbert Blumer offers a re-statement of the principles of Mead's symbolic interactionism in terms of the larger social world and sociological methodology which is of help here (Blumer, 1986, p. 21). Blumer draws on Mead to emphasise the way meaning and the social origins of the self in a symbolic interactionist account are constituted by symbolic social processes (1986, p. 4, 12). He argues that symbolic interactionism rests on three premises:

The first premise is that human beings act toward things on the basis of the meanings that the things have for them... The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters (1986, p. 2).

Blumer also emphasises the located interaction of humans, "The actor selects, checks, suspends, regroupes and transforms... meanings in the light of the situation in which he is placed and the direction of his action" (1986, p. 5). In everyday interaction, this situation may involve other people, of whom the actor takes account:

human beings in interacting with one another have to take account of what each other is doing or is about to do; they are forced to direct their own conduct or handle their situations in terms of what they take into account (1986, p. 8).

It is important to note here the social interactions necessary in the production of meaningful "self-objects." Identity formation arises out of symbolic interaction – "The human being is seen as "social" in a... profound sense" (1986, p. 14). The next relevant aspect of Blumer's approach is his

portrayal of the broader society from a symbolic interactionist perspective. In beginning this portrayal, Blumer offers a sophisticated portrait of the work he inherited from Mead, and, within this work, the lack of a convincing macro-picture of society (1986, p. 61). Blumer sets out to map such a theoretical scheme of human society (Lyman and Vidich, 1988). He uses the phrase “joint action” to refer to collective acts of symbolic interactions, including social actors in various social positions (1986, p. 71).

The life of any human society consists necessarily of an ongoing process of fitting together the activities of its members. It is this complex of ongoing activity that establishes and portrays structure or organization (1986, p. 7).

According to his analysis, from joint action emerges social structure: “A society is seen as people meeting the varieties of situations that are thrust on them by their conditions of life” (1986, p. 72).

The central benefit of Blumer’s account is his ability to move from Mead’s philosophical expression of symbolic interactionism into a valid sociological perspective, one which we may apply to interview texts in this thesis (Plummer 1990; 1991), contributing to the concept of identity formation. Blumer also offers a better picture of the relationship between self and society than Mead; as noted, he attempts to theorise the role of society in relation to the self. This aspect of Blumer’s work can help provide a social context for understanding the processes of diagnosis, rebuilding a sense of identity and identity maintenance.

There still remain a number of issues to be treated. Blumer fails, like Mead, to provide an analysis of the emergence of pathological selves, subcultures and deviant groups. At this point we may stop to observe that Rosenberg (1984, 1992) *does* draw on a symbolic interactionist perspective to account for the definition of pathological (“insane”) selves as defined by a failure to take roles in social interaction. For Rosenberg, schizophrenia would be defined by a failure to role-take in thoughts, emotions and behavior (Cf. Hooley, 2010, for a discussion of social abilities that can be impaired in schizophrenia). In light of Rosenberg’s work, we must acknowledge that symbolic interactionism may

be developed to provide an analysis of dysfunctional selves. However, Rosenberg's work does not account for the full range of behaviours outlined by symbolic interactionism that may be compromised by serious mental illness. I will attempt to do precisely this in Chapter 9.

Tied to the problem of pathological selves, although Blumer discusses the role of society in self-formation, he fails to provide a thorough picture of the impact of power and hierarchy in the processes being studied. Nor does his work focus on the social context of meanings relevant to a symbolic interaction; he fails to account for how the institutions and structures of social context take on a causative and ontological life of their own. Such is admitted by Dennis and Martin (2005, p. 210) who describe symbolic interactionism's approach to conceptualising sociology at the macro level:

[S]ymbolic interactionism rests on a principled refusal to deal in the supposedly universal, objective and metaphysical categories and concepts which have produced little more than confusion in philosophy and sociology.

It is the purpose of this thesis to provide an analysis of how power suffuses the relationship between the patient and the psychiatric apparatus; this task is approached below.

So far, we have considered symbolic interactionism from the relatively theoretical perspectives of Mead and Blumer. It is worthwhile at this point to consider a perspective on mental illness that has absorbed the interactionist focus of symbolic interaction, namely Thomas Scheff's *Being Mentally Ill: A Sociological Theory* (1984). This text does seek to offer an interactionist account of dysfunctional selves. Here, Scheff proposes that the existence of mental illnesses, like schizophrenia, arises out of processes of deviancy and labelling. More specifically, Scheff argues that the career of the so-called mentally ill arises out of a process of "residual rule-breaking" (p 53) and subsequent labelling by the psychiatric apparatus and society generally (Cf. also Lemert, 1962, who argues that paranoid psychosis is reinforced through exclusionary dynamics in social institutions). Scheff observes that "insane" behaviours are in fact learnt and absorbed by children from an early age, and that the mental patient exhibits these behaviours as a result of interaction with psychiatrists, mental health

professionals and other authority figures. Scheff's argument is interesting and mildly persuasive. He certainly possesses insight into the sociological nature of mental illness, that is how the social impacts upon the definition and classification of behaviours as mentally ill and the power played by sources of authority. However, his argument suffers from several flaws. The suggestion that mental illness is an expression of behaviour learnt as a child, rather than derivative of some biochemical process, is weak. One may criticise the text on the grounds that there appears to be (growing) evidence that mental illnesses such as schizophrenia are caused at some level by neurochemical brain processes (Gove 1980, 1984). Furthermore, his position is essentially externalist. It offers a theory of mental illness from the outside, from the point of view of socially imposed norms and expectations, and does not engage with the subjective experience of the mentally ill person. As such, the argument that symbolic interactionism does not offer a sufficient analysis of pathological selves still stands.

Having dealt with Scheff's theory of labelling, there also exists a relevant literature of writers using symbolic interactionist principles to address expressions of chronic illness, overcoming the key problem that pure symbolic interactionist accounts do not refer sufficiently to deviant or pathological identity states. This literature provides us with concepts for understanding the experience of schizophrenia as a chronic illness, and one where identity is particularly under threat. In particular, this material provides the tools to understand narratives regarding illness developed by people diagnosed with schizophrenia.

Reconstructing Identities

One of the most significant aspects of the interactionist literature lies in accounts of how people diagnosed with chronic illness "reconstruct" their disrupted biographies (McCall and Wittner, 1990; Skultans, 2000). In later chapters, the writer will use this account to help understand the disruption

and rebuilding of identity that can occur in cases of schizophrenia. Certainly the intensity and success of such reconstruction will differ with regards to the intensity of the schizophrenic episode and the success of medication. Nevertheless, it is important to examine how people who have suffered biographical disruption may come to reconstruct their relationship with themselves and others, their goals and their personal values. Indeed, this reconstructive process is a vital part of the rebuilding and maintaining a sense of identity that forms the key research interest of this thesis, and is engaged with later in Chapter 6, 7, 8 and 9.

The phenomenon of reconstruction has been addressed by a range of writers from a number of perspectives (Gergen and Gergen, 1983 and 1986; Williams, 1984; Strauss and Corbin, 1987; Corbin and Strauss, 1991; Frank, 1997; Bury, 2001; Faircloth et al. 2004; Harris, 2009; Locock et al, 2009). These approaches are broadly similar; certain themes re-occur. They include the themes of the importance of narrative in the reconstructive process; the need to re-examine and re-fashion personal narratives of the person with illness; the loss of and grieving for abilities and desires frustrated by illness; the importance of performance before others; the desire to re-establish a “normal” life; and, finally, the acceptance that certain elements of the self have been permanently lost or compromised by chronic illness (Greenfield et al., 1989). Frank (1998) accounts for illness as a form of “care of the self” in the Foucauldian sense; more of which will be said below. Simon Williams, in a 1984 article “The Genesis of Chronic Illness: Narrative Reconstruction”, (1984) argues that in the light of biographical disruption, a patient’s attempt to make sense of the “putative causes” (1984, p. 177) can be read as a form of reconstruction. This process can help rebuild a healthy relationship between “body, self and society”, as well as giving order to an illness that might be fragmentary or chaotic in effect. Michael Bury captures the essence of the process well in his 2001 article “Illness Narratives: Fact or Fiction?”:

Under conditions of adversity, individuals often feel a pressing need to re-examine and re-fashion their personal narratives in an attempt to maintain a sense of identity... Thus universal, cultural and individual levels of human existence are tied together with narrative threads (2001, p. 264).

Indeed, it is to Bury we look later for the first account of reconstruction through narrative.

In his 2001 article Bury proposes that people who have experienced biographical disruption may use one of three narrative forms to help understand the nature of their chronic illness (including causes and repercussions) and reconstruct their sense of self. These narratives are named “contingent”, “moral”, and “core”. The contingent narrative is one that “address[es] beliefs about the origins of the disease, the proximate causes of an illness episode, and the immediate effects of illness on everyday life” (2001, p. 263). The moral narrative is one that “provide[s] accounts of (and help to constitute) changes between the person, the illness and social identity, which help to (re)establish the moral status of the individual or help maintain social distance” (2001, p. 263). The core narrative is one that “reveal[s] connections between the lay person’s experiences and deeper cultural levels of meaning attached to suffering and illness” (2001, p. 263). These three, inter-connected narrative forms may help the disrupted person understand and come to terms with his or her chronic illness; they will be deployed later in this thesis. There is no reason we cannot apply the framework of these three narratives to the accounts given by participants in the study. Indeed, the moral narrative, with its focus on social identity as the status of the individual, seems well suited as a conceptual tool with which to explore how people form and maintain identity in the light of the diagnosis of schizophrenia. It is also worth noting that Bury draws on Robinson (1990; Cf. Robinson 1988) to argue that these narratives may have a “stable”, “progressive” or “regressive” quality⁹. These qualities are fairly self-explanatory: a stable narrative is one where the speaker remains on a steady trajectory regarding their illness and life goals; a progressive narrative is one where the speaker has made or is making positive progress with their illness and towards their life goals; a regressive narrative is one where the illness is worsening and the speaker is moving away from life goals. See Frank (1997) for a similar distinction between “restitution”, “chaos” and “quest” narratives.

⁹ See Frank, 1997, for a similar distinction between “restitution”, “chaos” and “quest” narratives.

One key concept that emerges through the literature on reconstruction after biographical disruption is “biographical work”. Felde (2011) writes from an “ethnomethodology-informed, social constructionist perspective” (2011, p. 105) that biographical work “constructs a subject who is continually working building situationally-appropriate identities from episode to episode” (2011, p. 103). He describes the “rhythms of life” (2011, p. 104) around which identities are constructed and re-constructed. Sanders *et al.* (2008) argue for the importance of the “biographical context of illness experience” (2008, p. 990) and “the construction of narratives” (1987, p. 991). Strauss and Corbin (1987) write of “biographical accommodations” (1987, p. 251) as “action aimed at achieving a sense of control and balance over that life, as well as giving it continuity and meaning despite the illness and the changes it brings” (1987, p. 251). This reintegration contains a process of “letting go, closure and grieving for what was lost”, with a corresponding movement to “a new self, a better self, even a transcendent self” (1987, p. 271). Strauss and Corbin suggest that only the biographically disrupted person can reconstruct their life, although others may help with “identity boosters, mitigating performance failures, and so forth” (1987, p. 264). They also identify four categories of “biographical work”. Strauss and Corbin say of these categories that “[a]lthough analytically distinct, each occurs simultaneously and feeds directly into the others” (1987, p. 265). The categories are: *contextualising* (incorporating the illness trajectory into the biography); *coming to terms* (arriving at some degree of understanding and acceptance of the biographical consequences of actual or potential failed performances); *identity reconstitution* (reintegration of the identity into a new concept of wholeness around the limitations in performance); and *biographical recasting* (giving new directions to the biography). These categories of action all interest us as they impact upon rebuilding and maintaining a sense of identity amongst people diagnosed with schizophrenia. As seen in Chapter 9, “biographical work” – as well as the other processes affecting identity described here – provides a basis to suggest a new concept of “identity work”. Identity work may at this stage be thought of broadly as the activities a person with identity-threatening illness engages in to re-build and maintain their sense of identity.

In their 1991 article “Comeback: The Process of Overcoming Disability,” Corbin and Strauss develop the concept of “comeback”. Comeback occurs when recovery¹⁰ manages:

to reconnect the body and the person of the past with the body and the person of the present through possible performances, while accepting that certain performances may no longer be possible and that other performances have a changed nature (1991, p. 239).

These performances that “may no longer be possible” also lose the significance they gave to the ill person’s biography. Nevertheless, comeback involves overcoming disability¹¹ through “medical’, “rehabilitative” and “biographical” work. Our interest is in biographical work, although the three are inter-related. Biographical work involves “biographical accommodation’, through which the ill person and those close to them “take action to retain and/or regain some degree of control over biographies rendered discontinuous by chronic illness” (1991, p. 251). The self which emerges from this process is involved in a continual reconstruction of events and actions. Recalling Kathy Charmaz (1997), discussed in Chapter 3, Corbin and Strauss also emphasise that the ill person may have a changed relationship with time, involving a planning and “juggling” with time to include “trajectory management’, as well as daily tasks. Locock *et al*, in their 2009 article “Biographical Disruption, Abruption and Repair in the context of Motor Neurone Disease”, emphasise the importance and frequency of “reconstruction” in the case of chronic illness. Although they do not use the specific term “biographical work”, they nevertheless discuss the narrative actions taken by those with motor neurone disease to help re-establish a sense of self and full identity, often replacing new activities for old activities they are no longer able to complete. Kernis and Goldman (2003) emphasise a number of factors that can affect the construction and stability of self-esteem; these include social comparison, feedback, and actions by the diagnosed individual. They also argue that people with

¹⁰ There exists a vast empirical literature concerning the process of recovery from mental illness (see, for example, Corring, 2002; Deegan, 2005; Jenkins and Carpenter-Song, 2005; Davidson et al., 2009), particularly emphasising the need for work from the perspective of the person with mental illness (Coursey et al. 1995). This literature is informed by a broad range of theoretical and methodological approaches, but because it does not intersect directly with the theoretical questions of interest to this thesis I do not have sufficient space to engage with it here.

¹¹ NB: Corbin and Strauss speak of physical disability, not psychiatric disability.

unstable self-esteem will be more likely to experience depressive episodes, be affected by negative events, be protective of their self-esteem and have more impoverished self-concepts. Devos and Banaji (2003) argue that there is a strong connection between identity development and membership in social groups; in particular, small “ingroups” such as small communities or families. There are certainly a number of approaches to chronic illness in the symbolic interactionist literature. For the sake of clarity, this thesis focuses, in particular, upon the work of Bury on illness narratives, and the concept of biographical work, considered below.

CHAPTER 4

Theoretical Perspectives: Illness, Schizophrenia, Identity and Embodiment

Having focused on broader sociological theories relevant to the issues of this thesis, it remains to be seen how more specific sociologies of illness allow us to theorise the relationship between identity and schizophrenia. The sociology of illness provides a number of insights into both mental illness and chronic illness more generally, and it allows us to draw more specific theoretical outlines within which to study the responses of interviewees. In particular, the concepts of “illness trajectory” and “biographical disruption” provide a framework within which to study interviewees’ experiences of schizophrenia and provide us with tools to help unpack the complex relationship between illness, identity and schizophrenia. The concept of “biographical disruption” speaks to the challenge to selfhood experienced by many people during the crisis and aftermath of a schizophrenic episode, that is throughout the phases of pro-drome, diagnosis, hospitalisation and treatment. Indeed, the idea of biographical crisis is of particular relevance with respect to schizophrenia, as it is often by its very nature an illness where the biography of personal identity is at stake, and the self is compromised. Biographical disruption, or crisis, also emerges in sociological studies of the impact of diagnosis and hospitalisation. As useful as these concepts from the sociology of illness are, however, they do not always capture the embodied, emotional breakdown that characterises many of the symptoms of schizophrenia. In this regard, the school of philosophy known as phenomenology provides a number of useful concepts. In particular, the work of Merleau-Ponty provides conceptual tools to pull apart and examine the lived, embodied experience of many people with schizophrenia.

Illness Trajectory

Anselm Strauss et al. (1984) offer a close, detailed account of chronic illness and identity, which focuses in particular on the concept of “illness trajectories”. The trajectories of chronic illness can vary, depending upon seriousness of illness, successful medication, familial and communal support, and so on. Strauss et al. differentiate between the “course of illness” and “illness trajectories”:

[The concept of course of illness] offers no problem to anyone, since we have all experienced an illness that did not merely appear but developed gradually over time, getting worse and then stabilizing or perhaps relatively clearing up. *Course of illness* is also a professional term, since to knowledgeable medical, nursing and technical staffs each kind of illness has its more or less characteristic phases, with symptoms to match. In contrast, *illness trajectory* is a term coined by the authors that refers not only to the physiological unfolding of a sick person’s disease, but also to the *total organization* of work done over that course, plus the *impact* on those involved with that work and its organization (1984, p. 64; emphasis included).

The concept of the illness trajectory is a useful one. It allows us to guide the analysis of research data within a broad framework, each disparate aspect of the illness of schizophrenia related to the other through the over-arching frame of illness trajectory, while also allowing for an analysis of the illness’ impact on the subjective experience of the patient and recognising the work done to respond to the illness. This thesis also makes use of what may be thought of as a “typical” illness trajectory for a person diagnosed with schizophrenia. This would include a pro-dromal phase where symptoms first emerge; diagnosis by a general practitioner or psychiatrist; stabilisation in a hospital or clinic; medication; and, in most cases, release to live with family or otherwise in the community. Illness trajectory may vary from person to person diagnosed with schizophrenia, in intensity and duration of various phases.

Illness trajectories can interact with identity in complex ways (Pettie and Triolo, 1999). At one level, the chronically ill person must adapt his or her self-concept to the reality of his or her illness and the difference in routines it brings – what Strauss et al. call “coming to terms”. Ill people with chronic illness will often undergo a process where

the experience reflected in the common complaint made by blind and physically handicapped men and women: people assume that they cannot act, work, or be like ordinary mortals... Nonsick persons, especially strangers, tend to overgeneralise the sick person's visible symptoms (1989, p. 81).

Such a process would seem to hold, not only for people with chronic illness, but also for people with visible symptoms or medication side-effects of schizophrenia, and is examined below in the section dealing with diagnosis and stigma.

The work of Jeffrey Ball et al. (2005) complements Strauss et al.'s theory of illness trajectory. Ball et al. consider a "theory of crisis for individuals with severe persistent mental illness". Their theory identifies four steps (2005, p. 12):

1. Underlying vulnerability
2. The crisis: Being overwhelmed and lacking control
3. Immediate responses
4. Crisis resolution and prevention

These four steps map neatly onto the typical illness trajectory we have identified for people with schizophrenia: underlying vulnerability represents the pro-dromal phase; the crisis represents diagnosis; immediate responses represent stabilisation in a hospital or clinic with medication; and, crisis resolution and prevention represent release to live with family or otherwise in the community.

Ball et al. describe a number of factors that may impact upon identity throughout this trajectory: agitation, anger and aggression; being low; feeling anxious; and euphoria.

Finally, the illness trajectory of people with psychotic illness is also treated in David Roe's (1997) PhD thesis *Exploring the Relationship between Individuals' Experience of Self and the Course of their Disorder*. Roe's work involves a substantial study of a group of 43 people who were hospitalised for severe mental illness with psychotic features, examining the relationship between self-esteem, engulfment and course of people's disorder. This study shows "only limited support for the hypothesis that levels of patients' engulfment and self-esteem shortly after discharge could predict

outcome at one-year follow-up” (1997, p. 60-61). Roe concludes that more information is required, and turns to a qualitative study involving semi-structured interviews of the research subjects, focusing on the relationship between self and course of the disorder. His central argument is that:

There seems to be an interactive relationship between the experience of self and the course of disorder, which includes ongoing complex mutual influences. Psychosis and its aftermath pose a major challenge to individuals' self-concept and core identity and often generate a diminished sense of self and resignation (1997, p. 101-102).

The use of the terms “interactive” and “mutual influences” are important insofar as they recognise that the patient may have some agency or ability to negotiate his or her position with a psychiatrist, in a clinic or hospital (Seale et al., 2006). The theme of the patient’s agency is one taken up below, as well as in Chapter 6, 7, 8 and 9. Roe’s work also suggests that the length and intensity of phases of psychotic illness may diverge for different sufferers of psychotic illness. This thesis will proceed upon the assumption that significant divergence in symptoms and drug side-effects may be found amongst different people diagnosed with schizophrenia.

The literature regarding illness trajectory does not provide a strong analysis of relations of power and social structure in relation to illness. Whilst it is true that Strauss et al. discuss the work of patients and kin when hospitalised – included in “the *total organization* of work done over that course, plus the *impact* on those involved with that work and its organization” (Strauss et al, 1984, p. 64; emphasis included) – much more could be said of contemporary power structures such as the doctor/patient relationship and the influence of the pharmaceutical industry. This thesis will explore such power structures; in particular, it will interrogate the diagnostic psychiatrist/patient relationship and will consider such structures of power as those involved in social control of people with schizophrenia, deinstitutionalisation and psychopharmacology.

We have seen that chronic illness such as schizophrenia may be analysed with the concept of illness trajectory. An important element in such a trajectory is the subjective experience of the illness by

the person who is ill. The following sections discuss the literature pertaining to the impact of chronic illness upon identity, and then, more specifically, the impact of schizophrenia upon identity.

The Impact of Chronic Illness on Identity

Michael Bury offers an analysis of the impact of chronic illness upon the biography, identity and self of people with chronic illness. In the course of this analysis, Bury (1982) develops the concept of “biographical disruption” as a way of describing the challenges to self-hood felt by many with chronic illness. Bury writes of biographical disruption:

My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support... Further, the expectations and plans that individuals hold for the future have to be re-examined (1982, p. 169).

The concept of biographical disruption offers insight into processes of dislocated identity experienced by those with chronic illness and is, in this thesis, translated beyond the realm of chronic illness to specifically address the breakdown of self in schizophrenia. However, the concept of biographical disruption may need to be extended to account for the severity of breakdown of the self in a number of experiences of schizophrenia. Indeed, in some cases of schizophrenia, the breakdown of identity moves beyond mere disruption of an ongoing life history into a profound collapse of self-hood. The concept of “biographical crisis” will be addressed in more detail in the Chapter 9.

Bury identifies three types of disruption in response to the “unfolding” of a chronic illness:

First there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries... Second there are more profound disruptions in explanatory systems normally used by people, such that a *fundamental re-thinking of the person’s biography and self-concept is involved*. Third, there is a response to disruption involving the mobilisation of resources (1982, p. 169-170, emphasis added).

The highlighted disruption concerning the “person’s biography and self-concept” is of most interest to this thesis, allowing as it does a theorisation of processes of rebuilding and maintaining a sense of identity in response to the chronic illness of schizophrenia. Bury (1982: 172-173) also noted the problem that many people experiencing biographical disruption have difficulty separating their sense of self from the disease. For many the disease had imposed on them to the point that they *were* their condition – they *were* arthritic, they *were* cancer carriers, and so forth; “a strict separation of disease and self... is precarious” (1982, p. 173; Cf. Yanos et al., 2010). We can assume that this kind of identification with the illness would be even stronger in the case of mental illnesses such as schizophrenia, where the self itself is often compromised. Indeed, Pilgrim (2007, p. 540) argues that physical illness is something which is deemed to “happen to” a person, whilst mental illness “implicates the whole self”. In light of such severity, this thesis offers the concept of “biographical crisis” as a way of conceptualising the more comprehensive crisis experienced by at least some people with schizophrenia. In Chapters 6, 7 and 8, we will see how such identification emerges in the accounts of illness offered by some of the research subjects interviewed.

We may expand upon the concept of biographical disruption through a reading of Michael Kelly and David Field’s paper “Medical Sociology, Chronic Illness and the Body” (1996). They argue that there is a strong connection between compromised identity and the compromise of bodily aspects of the self in chronic illness, especially during the sometimes drastic bodily changes of chronic illness (Cf. Charmaz, 2000; Larsen et al, 2006). They argue that there was, at the time of writing, an under-theorisation of “bodily experiences in everyday life” (1996, p. 243) in contemporary sociology – a gap in the literature this thesis seeks to address. Such theorisation of bodily experiences, in the context of schizophrenia, is not always well captured in the symbolic interactionist approach, focusing as it does on cognitive and communicative processes. However, as outlined in Chapter 9, this thesis seeks precisely to extend symbolic interactionism to account for emotional and embodied

experiences of schizophrenia which we might define, for want of better expressions, in terms of “emotional interactionism” and “embodied interactionism’.

We may further interrogate the literature concerning the impact of chronic illness. In her 1983 article “Loss of Self: A Fundamental Form of Suffering in the Chronically Ill”, Kathy Charmaz offers an analysis of “loss of self” in the chronically ill. Charmaz argues that the visibility of suffering can cause discomfort to friends and acquaintances; the illness “rips away the previously known public, sociable presentation of self” (1983, p. 179). This phenomenon would seem to apply particularly well to people exhibiting visible symptoms of schizophrenia such as delusional thoughts, hallucinations, confused speech, catatonia, and other similar symptoms. In such cases, subjects with schizophrenia may resort to “passing” or “concealing” of stigmatic signs as discussed by Goffman (1963). Such processes are discussed below in the section on diagnosis and stigma, and emerge clearly in Chapter 8. Moreover, the breakdown in the “public, sociable presentation of self” may further compromise relations with family and friends that would otherwise have been useful in the rebuilding of identity after a biographical crisis.

Beyond these issues, Charmaz also argues that chronic illnesses can be thought of in terms of “interruptions”, “intrusions” or “immersion”. Immersion typically leads to a “recasting” of life (1997, p. 79), and a turning inward (1997, p. 99). It seems fair to say that the experience of schizophrenia tends to be immersive given that such experience can inhabit the entirety of the person’s identity; it constitutes more than an interruption or intrusion. This theme certainly emerges in Chapter 6, 7 and 8, especially with the turning inward of social isolation¹². Finally, but not of least importance, Charmaz points to “developing a dialectical self” (1997, p. 70), where there is an ongoing reflexive relation between the “sick self” and the “monitoring self”. Interestingly, Charmaz compares this dialectic to the relationship between the “I” and “me” in the work of Mead. The comparison

¹² For an early discussion of social isolation as a social factor concomitant with schizophrenia, see Jaco, 1954.

suggests that a division may exist within the identity of some who are ill; a division between the self absorbing social experiences of illness and the self acting upon that experience. The comparison also supports the usefulness of the “I” and “me” concepts. As we will see, Mead’s work on symbolic interactionism forms a fundamental element in this thesis’ approach to theorising and analysing the experience of people diagnosed with schizophrenia.

We have seen that chronic illness can have a significant impact upon the identity of the person with the illness. In some cases, biographical disruption may occur. The self of the person with chronic illness may become immersed in the illness. However, we have also already seen that the illness of schizophrenia may bring with it an even more significant breakdown of the self – a kind of biographical crisis. The following section examines this line of thought, discussing the impact schizophrenia specifically can have on identity.

The Impact of Schizophrenia on Identity

It has been observed that schizophrenia has perennially been an object of interest for psychiatry (Woods, 2011), if not in broader culture. It comes as no surprise then that there exist a number of strong accounts of the impact of schizophrenia on identity.

Ronald Laing’s seminal work *The Divided Self* (1990) offers a complex portrait of the effect of schizophrenia on the self. In his text, Laing attempts to offer an “interior” account of schizophrenia – a view “from the inside”. For Laing, schizophrenia (particularly in the pro-dromal stage) typically leads to a division of the self (1990, p. 39). Laing delays the concept of “ontological security” to illustrate what breaks down in the divided self. “Ontological security” may be thought of as a sense

of wholeness or fullness in a person's being¹³. The person is not divided; he or she is not lacking a vital element of self-esteem or self-fulfilment. In contrast to this, "ontological insecurity" arises where there is some lack or division within a person's identity. This can be a sense that one is not whole, that one's mind or self is fragmented, that one is lacking a crucial element of self-hood or self-fulfilment. The person suffering identity breakdown in schizophrenia is a classic example of someone lacking ontological security, and the concept is used in this thesis to explore the experience of biographical disruption and biographical crisis.

Laing divides ontological insecurity of the person with schizophrenia into three, overlapping categories that will prove useful for the analysis of research in this thesis. The first is "engulfment" – experienced as a loss of identity, or the threat thereof: "to be enclosed, swallowed up, drowned, eaten up, smothered, stifled" (1990, p. 45). The second is "implosion", which occurs when one experiences the external world as impinging dangerously on the inner world: "the full terror of experience of the world as liable at any moment to crash in and obliterate all identity as a gas will rush in and obliterate a vacuum" (1990, p. 45). The third is "petrification" or "depersonalisation". To feel petrified or depersonalised is to fear that one's identity will become nullified or exterminated: "...the possibility of turning, or being turned, from a live person into a dead thing, into a stone, into a robot, an automaton, without personal autonomy of action, an *it* without subjectivity" (1990, p. 46). To experience one of these situations sounds horrific, and may go some way toward explaining the intense fear and misunderstanding associated with schizophrenia by some members of the public. These three situations also resonate with the reported experiences of self-hood by research subjects as detailed in Chapter 6,7 and 8. This thesis will take these situations as evidence of a disruption or breakdown of identity, and lend weight to the development of the concept of biographical crisis.

¹³ See Doubt, 1996, for a discussion of the relationship between Laing's concept of ontological insecurity and Hegel's concept of the Unhappy Consciousness.

Lysaker and Lysaker also contribute to an understanding of the impact of schizophrenia upon the self. In their 2008 book, *Schizophrenia and the Fate of the Self*, they outline the impact of schizophrenia on identity through the concept of “self as dialogue”. This concept posits that people hold “self-positions” and express these through dialogue (2008, p. 43-62). Such dialogue can contribute to “life histories” that help the subject make sense of his or her life experience, and illness experience. The text that seeks to outline how these self-positions, and the dialogue that expresses them, can be compromised by schizophrenia. Such compromise typically emerges in a “diminished sense of self” (2008, p. 35), expressed in apparently disordered or interrupted dialogue and can lead to a case where subjects “find themselves engulfed and overwhelmed by their illness” (2008, p. 76). One can discern a clear proximity here with Laing’s concept of ontological insecurity.

Lysaker and Lysaker outline three forms of “self-experience” that may emerge in schizophrenia as they have conceptualised it. First they identify *the monological self*, where:

a significant decrease in the interanimating play of self-positions due to the inflexible dominance of one or two self-positions. In such cases a rigidly unchanging hierarchy emerges in which self-world interactions are consistently ordered in a singular manner, and intra- and interpersonal dialogue is replaced by a monologue (2008, p. 81).

The barren self, where subjects express themselves:

in ways that lack even the singular focus... of monological self-presentations. Instead, it is as if they are ciphers through which disjointed remarks and actions flow... [they are] empty, disjointed (2008, p. 85).

The cacophonous self, where:

certain people suffering schizophrenia find themselves in a swirl of self-positions that seem to proceed without any order at all (2008, p. 86).

These forms of self-experience are noted in Chapter 6. Lysaker and Lysakers' argument is supported by a number of case studies. This intensity of “self-experience” sharply distinguishes identity phenomena in schizophrenia from that experienced in chronic illness or non-psychotic mental illness, where one’s very sense of self is not in crisis. Again, the Lysakers’ findings support the development of the biographical crisis concept.

Davidson and Strauss (1992) offer an even-handed account of the effect of severe mental illness on the person suffering the illness. They describe a “distortion in sense of self” as an essential characteristic of schizophrenia (1992, 132). Davidson and Strauss also advert to the process of recovering from biographical disruption in severe mental illness. They suggest that:

[T]he process of rediscovering and reconstructing an enduring sense of self as an active and responsible agent provides an important, and perhaps crucial, source of improvement. This process of becoming aware of a more functional sense of self and building upon it in the midst of persisting psychotic symptoms and dysfunction is alluded to over and over again by persons suffering from these disorders (1992, 131).

The focus on an active agent recovering from the disruption of illness will become important in Chapters 6, 7, 8 and 9, the Discussion Chapter, where the concept of “identity work” is suggested to describe such activities.

We may find further insight into the effect of schizophrenia upon the subject in an issue of the *Schizophrenia Bulletin* (1989, p. 15(2)) dedicated to the topic. The issue of the Bulletin is introduced in a foreword by John Strauss and Sue Estroff (1989), where the authors exhort theorists and researchers to delve more deeply into the qualitative, subjective experience of schizophreniform disorders to gain a better insight and to help with the treatment and healing of these disorders. In another article by Sue Estroff (1989), “Self, Identity, and Subjective Experiences of Schizophrenia: In Search of the Subject”, Estroff echoes the point made above that “Schizophrenia is an *I am* illness – one that may overtake and redefine the identity of the person” (1989, p. 189; emphasis included). She argues that social science may have valuable input into understanding this redefinition – a position endorsed by this thesis. This redefinition is again one that will generally not occur in chronic illness or non-psychotic mental illness, largely because they do not carry the stigma or the nature of comprehensively subsuming identity present in schizophrenia.

Finally, we may refer to Doubt, who also considers the fate of the self in schizophrenia. In his 1992 article titled “Mead’s Theory of Self and Schizophrenia” (Doubt 1992) he argues that:

What is painful about watching schizophrenics struggle with their illness is that we watch how the illness constitutes a serious invasion of the self. What is uniquely tragic about schizophrenia is that it directly confronts the character of the human self and so the ability of the human self to be itself (1992, p. 310).

Whilst this literature paints a frankly horrifying picture of identity in schizophrenia, we must be careful not to assume that all cases will involve the kind of failures or breakdowns described in this literature. The experience of people diagnosed with schizophrenia may actually range from less to more intense symptoms; those with fewer symptoms may not experience the horror of engulfment, implosion or petrification. This thesis seeks to be open to such divergence. It is also unclear if the categories presented, such as the petrified self or the monological self apply to the whole spectrum of schizoid disorders. It appears that the categories may not apply to schizoaffective disorder or schizoid personality disorder, for example, where a grave threat to the self is not present.

This chapter has charted the literature concerning the impact of schizophrenia upon identity. A picture of a highly compromised self, in many cases, has emerged. However, processes affecting the identity of the person with schizophrenia are not limited to the illness itself; the social context in the form of diagnosis may also impact the self. The following section accordingly examines the impact of diagnosis upon the identity of the person with schizophrenia.

Diagnosis and Identity

Diagnosis is typically seen in the literature as a turning point in the patient's experience of identity disruption. Bury (1982) notes that the onset of chronic illness may be insidious. It is thus difficult to identify a significant moment where the entire biographical disruption takes place. However, such disruption often emerges during the process of diagnosis, at which point the person diagnosed with schizophrenia may be experiencing biographical crisis. Pilgrim (2007, p. 540) emphasises the importance of diagnosis, both in physical and mental disease.

Treating the subject of diagnosis directly, Yvonne Hayne (2001) presents *To be Diagnosed: The Experience of Persons with Chronic Mental Illness*, a work highly relevant to exploring how identity breaks down during diagnosis of chronic mental illness. Hayne delves into the experience of diagnosis of a chronic mental illness amongst a relatively small number of people. She makes clear the significance of diagnosis at a number of levels:

[A]s the pain, grief and loss fluctuate in intensity from day to day perhaps, the “prediagnosis self” becomes less and less recognizable. The individual must struggle to rebalance, to take stock of altered functions, to regroup. This is the only way to move forward and to move forward includes the challenges of finding a level of wellness within the illness and within the knowledge of the illness brought by diagnosis (2001, p. 17).

Hayne focuses our attention on such factors as having a previously un-diagnosed illness whose diagnosis provides confirmation, the creative experience of certain mental illnesses like bipolar disorder, personal resolution and defiant attitude at the outset, and the experience of being utterly “broken” by the diagnosis of chronic mental illness.

Hayne draws out from all her stories an emphasis on how diagnosis altered the being of the people being diagnosed – changes “of being and of character” (2001, p. 166) – and the related structural significance of diagnosis. Hayne distinguishes identity effects in diagnosis from those that occur in biological (non-neurological) illness; that is to say, Hayne emphasises that diagnosis of chronic mental illness goes to the heart of identity, while simple biological illness does not commonly have a profound effect on identity. Such an opinion is certainly apparent in Chapter 6, 7 and 8 of this thesis. Likewise Hayne draws out the theme of “broken-ness” in diagnosis and post-diagnostic experience – “broken-ness of history of relationship, of space, of future, of self-narrative, of spirit” (2001, p. 167). The experience of being broken chimes well with themes of biographical disruption and biographical crisis, as well as ontological insecurity that emerge in Chapter 6, 7 and 8.

Complementing the picture of diagnosis as a significant turning point in the illness trajectory, Charmaz emphasises the role of the doctor/patient relationship during diagnosis. Charmaz (1983) sees this relationship as an important indicator of the prognosis of the self in chronic illness. Interaction with a diagnostician may lead to a heightened self-concern. This may lead to scrutinising encounters with others for hints of discreditation and negative reflections of self; greater dependence on others; a need for social contact aligned with a lessening capability of maintaining relationships; and the “language of loss” expressing a heightened self-concern (1983, p. 190-191). Charmaz’s insights into diagnosis as a turning point will prove useful to this thesis. In particular, the emphasis on heightened self-concern and the number of ways the self is enmeshed within social relationships are valuable. Indeed, many of these processes emerged in the interviews with research respondents presented in Chapters 6, 7 and 8.

As we have seen, the experience and diagnosis of schizophrenia can have a severe impact on identity. Such impact may lead to biographical crisis; it may involve ontological insecurity and it certainly upsets the sense of self of the person with schizophrenia. This thesis now turns to some of the social structures and processes aside from diagnosis that affect the identity of the person with schizophrenia.

Schizophrenic Symptoms, Embodiment and Phenomenology

Schizophrenia is an illness that affects the way the sufferer experiences the world around them. Many people with schizophrenia experience hallucinations and delusions. These experiences are significant and often traumatic for the person undergoing them, and are worth analysing.

We may inquire into these experiences by engaging in phenomenological analysis. More specifically, we may take account of thinkers who have used phenomenology to gain an insight into the personal

experience of schizophrenia. The theorists Ludwig Binswanger, Eugene Minkowski and Louis Sass have used phenomenological techniques in this way, and their insights are considered here. The work of French phenomenologist Maurice Merleau-Ponty is also considered. Although he does not directly address the schizophrenic experience, his concept of an embodied being – in crisis or broken down by schizophrenia – offers further insight into the experience of schizophrenia. Before considering these thinkers, however, it is worth briefly giving an overview of the work of Edmund Husserl and Martin Heidegger, from whom these thinkers, in many ways, extrapolated their own philosophical positions.

Husserl sought to give thought about human beings a rigorous and scientific foundation (Husserl 1988). In order to achieve this goal, Husserl aimed to uncover the universal structures of human consciousness. With an understanding of such structures, Husserl believed that a firm foundation could be found (Spitzer and Uehlein, 1992). Pursuing this project, Husserl performed what he described as the “Transcendental-Phenomenological Reduction”. This reduction involved a process whereby Husserl sought to “bracket” the contents of conscious experience, engage with his own consciousness, and arrive at the underlying structures that made such experience possible. Through this process, Husserl held, one arrives at a “transcendental ego” – an inner subjective consciousness of all that one perceives. This transcendental ego is interesting because it not only explains the world (as the external experience of the transcendental ego) but also because it is not itself “of” that world - the nature of the transcendental ego transcends is wholly different from the world itself. In taking this position, Husserl echoes the work of René Descartes, who also searched for a secure foundation for human knowledge in the direct experience of consciousness (hence Husserl titles his work *Cartesian Meditations*). Another important aspect of Husserl’s position is the claim that all consciousness is “intentional”. That is to say, all consciousness is “directed” at an external object; all consciousness is “of or about something” (Romdenh-Romluc, 2011, p. 9; C.f. Wiggins et al, 1992).

Heidegger sought to uncover the nature of “being” (Heidegger, 1962). In particular, he was interested in the nature of the human being – a being that could inquire into the nature of its own being. To this end he sought, like Husserl, to find and illuminate the fundamental structures of consciousness. However, Heidegger moves significantly beyond Husserl. Rather than finding a transcendental ego, Heidegger finds and describes a “Being” that is already, and always, implicated in the world. This being is always engaged in projects in the world; its fundamental structures lie in temporality, spatiality, “thrown-ness” (the situation of being in the world) and its relationship to other beings. Heidegger describes this being as “Dasein”, roughly translated as “being-there”. Dasein is intrinsically connected to the external world, both as a pre-reflective consciousness and as a conscious actor, and is thus described as “being-in-the-world”. Where Husserl finds a consciousness separate and independent of the world, Heidegger finds a being fundamentally engaged with the world; a being that bridges the gap between subject (self) and object (world).

Binswanger draws heavily on both Husserl and Heidegger. From Husserl he inherits the focus on subjective consciousness as a basis for knowledge and an emphasis on the “life-world”. From Heidegger he borrows the term Dasein and the concept of a being-in-the-world. The influence of Heidegger is important; with the concept of being-in-the-world, Binswanger is able to transcend dualities of subject/object and internal/external. With Dasein, Binswanger also develops a conceptualisation of the human being that he is able to mingle with influences from Freud and psychoanalysis. The result is a process Binswanger describes as “Daseinanalysis”. Daseinanalysis is not so much a therapeutic tool (though it has later been used as such) as much as a methodological instrument that may be used to explore the psyche of people with mental illness. Binswanger uses the technique, notably in his text *Schizophrenie* (1957), to gain access to the experience of a number of people diagnosed with schizophrenia. Through Daseinanalysis, Binswanger is able to gain access to what he regards as the “schizophrenic existential pattern” (Binswanger, 1963, p. 252) – that is, the transformations of the Dasein over time in people diagnosed with schizophrenia. Binswanger

identifies four such stages of transformation, or development, in the schizophrenic existential pattern. The first is:

the notion of a breakdown in the consistency of natural experience, its inconsistency. Inconsistency implies precisely that inability to “let things be” in the immediate encounter with them, the inability, in other words, to reside serenely among things... What makes the lives of our patients such a torment is that they are not able to come to terms with the inconsistency and disorder of their experience but, rather, constantly seek for a way out so that order can be re-established (1963, p. 252).

This notion of “breakdown in the consistency of natural experience” certainly seems to capture the sensory disruption schizophrenia may cause, especially in the case of hallucinations. The second stage lies in:

the *splitting off of experiential consistency into alternatives*, into a rigid either-or... We thus come... to what we have come to recognise in all our patients as the formation of Extravagant ideals. The Dasein now stakes everything on “maintaining” this stance, on – in other words – pursuing this ideal “through thick and thin” (1963, p. 254; emphasis included).

Here, with the concept of “splitting into alternatives” we find a clear description of the fierce certainty with which a patient with schizophrenia may assert delusional belief. Furthermore,

Compared to the severe existential pull exerted by both of these alternatives, the inconsistency of experience was relatively harmless. For now the Dasein is torn by the struggle between both aspects of the alternative into which it is split. Now it becomes a matter of either being able to pursue the Extravagant ideal or of giving it up entirely (1963, p. 254).

The third stage involves:

the concept of covering. By this we mean the sisyphyslike effort to conceal that side of the alternative that is unbearable to the Dasein so that the Extravagant ideal might thereby be buttressed” (1963, p. 258).

Perhaps at this stage we may relate the concept of “covering” to Goffman’s concept of concealing stigma, discussed in the next chapter. The final stage comprises:

the existence’s *being worn away* (as though by friction), the culmination of the antinomic tension involved in *no longer being able to find a way out or in*, a culmination that is a *resignation* or a *renunciation* of the whole antinomic problem as such, and that takes the form of an existential *retreat*... We come now to the retreat from existence in the *completely* unfree mode of *insanity*, a mode in which the Dasein of its own free will renounces neither life nor social life. What rather is renounced is life as independent, autonomous selfhood. The Dasein thus *surrenders itself over* to existential powers alien to itself. What we have seen is a particularly radical capitulation of the Dasein... Now.... The Dasein removes itself from the autonomy of its own life context. We are forced to say of such a person that he is a victim, a plaything, or a prisoner in the hands of alien powers (1963, p. 258-259; emphasis included).

This final stage bears comparison to what Laing describes as the person with schizophrenia being engulfed or petrified, and clearly represents a change, if not breakdown, in everyday modes of self-hood. Importantly, however, and unlike Laing, Binswanger does not regard this process and its endpoint as a breakdown or failure of the Dasein. Rather he understands it as a *different* form of Dasein; one which the doctor or Daseinanalyst can access with patient and sensitive interrogation. As we will see, the concept of a self that is merely in a different mode of being, rather than fundamentally compromised or broken down, is not shared by Minkowski, Merleau-Ponty or Sass. We now turn to the work of Eugene Minkowski.

Eugene Minkowski engaged in a phenomenological project to help uncover the “essential phenomena” (Spiegelberg 1972, p. 234) arising in schizophrenia. Unlike Binswanger and Merleau-Ponty (considered below), Minkowski did not set about his task through a close engagement with the thought of Husserl and Heidegger. Indeed, Minkowski’s main acknowledged debt is to the philosopher Henri Bergson, who emphasised immediate experience and intuition as the basis of a firm philosophy. Nevertheless, Minkowski’s task is broadly phenomenological in manner; he seeks through close discussion, observation and analysis of a large number of case studies to reach the central, underlying experiences of people with schizophrenia. Like Sass, as we will see, Minkowski contrasts this task with a quantitative approach to the symptoms of schizophrenia, holding that a close, qualitative phenomenological approach to the data is called for. In pursuing this task over time, Minkowski comes to uncover what he described as the “*trouble generateur*”, the deep and central factors constituting the heart of the experience of schizophrenia (Urfer, 2001, p. 281-282; C.f. Sass, 2001, p. 256). Urfer on Minkowski¹⁴ argues that:

Phenomena at the level of *trouble generateur* poses a certain unique spatio-temporal configuration that is distinctive in each specific psychiatric disorder... It is the formal disturbance that is essential, that shapes the symptoms and provides what we would now call the validity criteria of nosological entities. The *trouble generateur*, as a formal-structural complex, may be considered to be analogous to the physiological substrate of symptoms in medical diseases (2001, p. 282).

¹⁴ There are unfortunately very few translations of Minkowski’s work from the original French.

This description of the “trouble generateur”, technical as it may seem, does attest to the particular form of disruption a person with schizophrenia may experience. Minkowski further characterises the loss of vital contact with reality that lies at the heart of the experience of schizophrenia. This, he describes as “*élan personnel*”:

There is a weakening of the dynamic, flexible, malleable aspects of [the] relationship [between the subject and the ambient world], with a corresponding predominance of the fixed, static, and rational elements of the spatial order. This can also be described as a lack of *attunement* to the inner and to the ambient world and a characteristic *arrest of existential temporality* (Urfer, 2001, p. 293; emphasis included).

We may relate this concept to Binswanger’s final stage of the phenomenology of schizophrenia, where resignation, renunciation and retreat characterise the phenomenological relationship with the world. Minkowski describes how this compromised relationship with the world leads to a form of autistic behaviour (or “*comportement*”). Minkowski distinguishes between “rich autism” (“*autisme riche*”) and “poor autism” (“*autisme pauvre*”). The first consists of a retreat from the external world into a rich, internal life of fantasy and dreaming, and typically proceeds into compensatory behaviour via excessive fantasy life, sulking or constant regrets (Urfer, 2001, p. 293). The second consists of a breakdown of the *élan personnel*, with a break from the world and a poor, empty internal life, and typically proceeds into sterile, “intellectuoid” attitude (Urfer, 2001, p. 293). Such a conception will chime well, as we will see, with certain experiences of disruption by research subjects. The result of the conception for Minkowski is a self that is fundamentally at odds with and disconnected from the world.

We now move to the work of Merleau-Ponty, in particular his *Phenomenology of Perception* (1962). Merleau-Ponty’s main interest is to develop Husserl’s position. He, too, searches for the fundamental structures of consciousness in order to secure a science of the human and the world. In doing so, Merleau-Ponty responds to what he describes as “Empiricism” and “Intellectualism”. Empiricism considers the world to be an external objective phenomenon, which can be experienced by the human subject; and considers that the human subject (particularly human consciousness) is

essentially consistent with material causation. Intellectualism, sometimes referred to by others as “idealism”, holds that the world can only be known through conscious perception (the world is not an external objectivity) and that consciousness is an essentially different type of thing than, and outside the world it perceives.

In response to these positions, and drawing on Husserl and various cases provided by then-contemporary psychology, Merleau-Ponty argues not only that the world is not an external objectivity, but that consciousness is not separate to the world. To sustain this position, Merleau-Ponty argues that the human being and the perceived world are one and the same thing. To wit, Merleau-Ponty argues that human perception of the world is both constitutive of the world perceived *as well as* the consciousness of the human. More specifically, Merleau-Ponty argues that human consciousness is located within the perceiving body, and that the body is irrevocably tied to the perception of the world. This situation can be described as being a “body-in-the-world”. The world and perception of the world are “mutually dependent parts of one whole” (Romdenh-Romluc 2011, p. 26). Merleau-Ponty writes “[t]he world is inseparable from the subject, but from a subject which is nothing but a project of the world, and the world is inseparable from the world, but from a world which the subject itself projects” (Merleau-Ponty, 1962, p. 430). Embodiment of perception is thus the pre-condition of a world to exist. In emphasising the body and embodiment in this way, Merleau-Ponty moves significantly beyond Husserl.

On the topic of the body, Merleau-Ponty also considers the issue that the perception of one’s own body differs in part from the perception of external objects. Perception, or consciousness, of the body is described as “proprioception”; it involves a spatial sense of the location of one’s limbs, perceptions of internal organs, the sense of hunger or tiredness, and balance, amongst other bodily qualities. Merleau-Ponty argues, however, that one’s proprioceptive consciousness emerges through

intentionality; that is to say, one becomes aware of one's body through bodily actions directed towards the world; hence the body-in-the-world (see for a discussion of intentionality Searle, 1999).

Merleau-Ponty further develops his position with regard to issues of actions, emotions, and the nature of thought. The common theme in this development is, again, embodiment. Merleau-Ponty argues that actions are embodied movements towards the world; intentional engagement of the body-in-the-world with the world as perceived. When not clearly intentional, acts can very often be determined by motor skills or habits ingrained in the body. Furthermore, what Merleau-Ponty describes as "motor intentionality" involves a direct, unmediated contact between the subject and the world (Romdenh-Romluc, 2011, p. 157). When one acts, one is not conscious *of* the act – one is conscious *in the* act. Emotions are understood as having motor intentionality and, again, direct unmediated contact with the world-as-perceived. Thought, argues Merleau-Ponty, is also tied closely to physical expression and the intentional existence of the body-in-the world.

Finally, we may briefly consider the problem of "other beings". Other beings (other people) can be understood as a problem insofar as they share with the original subject a body-in-the-world structure, but the perception of such structure is not available to the original subject. Merleau-Ponty must face the possibility that body-in-the-world may lead to solipsism. To counter-act such a possibility, Merleau-Ponty argues that the original subject perceives other subjects as beings with potential action and a shared being-in-the-worldness, what is sometimes described as "intersubjectivity". Indeed, intersubjectivity is something of an ontological pre-requisite for development of a healthy perceptual apparatus; for a functioning being-in-the-world. Indeed, the focus on relations with specific and general others in symbolic interactionism – explored in the following chapter – bears testament to the importance of intersubjectivity in the rebuilding of the self, and it is a theme which emerges strongly in Chapters 6, 7 and 8.

Having given an account of the phenomenology of Merleau-Ponty, we may consider the insight his position gives into the embodied symptoms of schizophrenia. Essentially, certain symptoms of schizophrenia constitute a breakdown of the body-in-the-world. The most common breakdown that we may relate to Merleau-Ponty's work lies in hallucinations about the world. Such phenomena constitute a vital breakdown in the subject's perceptions; the being of the sufferer is perceiving a world that is not actually "there". His or her perceptive apparatus is flawed. Indeed, hallucinations present more than mere misapprehension; they constitute an ontological collapse of the body-in-the-world – Laing's phrase "ontological insecurity" is wholly pertinent here. This type of breakdown can be ascribed to many common hallucinations, including "hearing voices", "seeing" things that are not there, tactile "feelings" such as the sense that one has bugs under one's skin, and so on. Importantly, the breakdown of body-in-the-world often takes a sensorial dimension; the body as perceiver of proprioceptive sensations is not working as Merleau-Ponty describes it. Such breakdown would include bodily sensations such as (again) bugs under one's skin, as well as what Laing described (earlier) as "petrification", where one believes or experiences the body as inert matter rather than the intentional location of being-in-the-worldness. Similar delusions of bodily breakdown again may be thought of as a failure of the Merleau-Ponty scheme of body/world. This raises the question of how to distinguish between delusions and hallucinations for the body-in-the-world. Certainly the hallucination – perception of something which is not "there" – is a clear breach of the being-in-the-world. Delusions – an inaccurate opinion about the world – on the other hand, may not constitute as obvious a break, since it involves a failure of belief, not embodied consciousness. However, delusions usually involve the mis-attribution of qualities to aspects or people in the world – believing that people can read one's thoughts, for example – and as such provide a clear, though perhaps lesser, breach of the perceiving body-in-the-world. Confused or disorganised thoughts, as well as confused expression (such as "word salad") constitute a breakdown of the embodied nature of thought and expression whilst misapprehensions such as the Capgras delusion (where one believe a close friend or family member has been replaced by an

identical-looking impostor) constitute a breakdown in the body's emotional apparatus and the "normal" engagement with the intersubjective world of other perceiving beings.

Finally, we may examine the work of Louis Sass. Sass, often in partnership with Josef Parnas, engages in a general phenomenological project to help uncover the underlying structures of the experience of schizophrenia (Ver Ecke and Grady, 1999). Like Minkowski, Sass does not engage heavily with the seminal thinkers of phenomenology such as Husserl or Heidegger. Sass takes phenomenology as an overall perspective:

[T]he purpose of phenomenology is to describe and define the nature and varieties of human experience rather than give an account of the causal mechanisms of efficacious processes that bring it about (Sass and Parnas, 2007, p. 63).

Sass and Parnas elaborate:

[W]e use "phenomenology" in the standard philosophical and continental sense; that is, to refer to the study of lived experience and how things manifest themselves to us within and through such experience... In psychiatric phenomenology, it is, of course, the subjective dimension of mental disorders that is of relevance... To grasp the mind of another person is to grasp the distinctive form of coherence of that person's consciousness; this requires that one move beyond mere static understanding of mental states toward an understanding of the unity of that person's subjectivity and its development over time (2007, pp. 64-65).

Using phenomenology in this way, Sass arrives at the conclusion that the experience of schizophrenia is dominated by mental phenomena affecting the sense of self in the person diagnosed with schizophrenia:

According to the view to be presented here, the core abnormality in schizophrenia is a particular kind of disturbance of consciousness and, especially, of the sense of self or ipseity that is normally implicit in each act of awareness (2007, p. 68).

Again, we find the theme of "disturbance" of the phenomenological subject in schizophrenia; elsewhere conceived as disruption or breakdown. The first such abnormality is termed "hyper-reflexivity". Hyper-reflexivity is described as "[A] kind of exaggerated self-consciousness, that is, a tendency to direct focal, objectifying attention toward processes and phenomena that would normally be "inhabited" or experienced as part of oneself" (2007, p. 68). The second abnormality is termed "diminished self-affection". Diminished self-affection is described as "[A] decline in the

(passively or automatically) experienced sense of existing as a living and unified subject of awareness” (2007, p. 68).

Sass argues that the first phenomena, hyper-reflexivity, causes the person with schizophrenia to objectify internal experiences that make up part of the self (Sass, 2003, p. 153). Sass further argues that hyper-reflexivity can be used to help explain the so-called “negative symptoms” of schizophrenia, such as poverty of speech, affective flattening, avolition and apathy. Such symptoms emerge in Chapter 6.

Sass’s argument regarding hyper-reflexivity begins with the contention that these symptoms, traditionally understood as a lack or deficit of some mental process, actually also involve positive phenomena, resulting in a need for a richer descriptive project:

A close phenomenological analysis suggests, in fact, that the characteristically schizophrenic abnormalities of experience defy any simple quantitative description and demand a richer and more qualitative set of concepts (2003, p. 155).

Sass continues to argue that hyper-reflexivity can cause a kind of mental stalling, or breakdown, in what would otherwise be automatic mental processes, leading to negative symptoms (these thoughts are present in a less articulated form in Sass (1987)). Likewise, diminished self-affection upsets the central (self)consciousness that Sass identifies as a fundamental element in the healthy psyche. The result of these two processes, often intertwined, is a “profoundly altered form of experiencing that is characteristic of schizophrenia” (Sass and Parnas, 2007, p. 81); a form of experiencing where the self is deeply compromised.

Before concluding this chapter, it is important to give an account of the 1996 work of Simon J. Williams, “The Vicissitudes of Embodiment Across the Chronic Illness Trajectory”. This article touches on a number of themes relevant to this chapter – including embodiment, chronic illness, biographical disruption and the illness trajectory – and, significantly, forms a “jumping-off point” for a discussion of phenomenology in Chapter 9. In this article Williams argues that:

[T]he typical course of the chronic illness trajectory involves a shift from an initial state of embodiment, one in which the body is largely taken-for-granted in the normal course of everyday life, to an oscillation between states of *dys*-embodiment (i.e. embodiment in a *dys*functional state) and attempts at *re*-embodiment; the latter involving considerable biographical work on the part of the individual (1996, p. 23).

Williams treats the person as embodied in the phenomenological sense of being-in-the-world.

Chronic illness throws this embodied nature into light through its impact on the person's bodily experience and disruption of his or her biography; an impact where the person becomes "*dys*-embodied, alienated and betrayed by [his or her body]" (1996, p. 26). Williams emphasises that this process is often not linear; that progress is both made and un-made over time, and that the failure of the body during chronic illness may be connected to a "loss of confidence in the self" (1996, p. 28). Re-embodiment "concerns the positive practical and symbolic actions which people take in order to restore meaning and counter the effects of symptoms and treatment" (1996, p 31). These actions include finding "meaning" in their illness, often through the "process of narrativisation", as well as more practical measures aimed at adjustment and coping. Such actions achieve a "negotiated settlement" between mind and body that may shift or change over the chronic illness trajectory.

What are we to make of these disparate phenomenologies? All claim to bring us closer to the schizophrenic experience; the essential structure of the disturbed consciousness. And yet the writers have produced a diversity of fundamental signs. Perhaps we can attribute this to the diversity of experiences captured over time by the moniker "schizophrenia". Perhaps the writers were biased by the case studies they chose to analyse. In any case, we can draw a common theme: a common emphasis on the compromise, a disruption of the self, be that self the transcendent ego of Husserl or the body-in-the-world of Merleau-Ponty. These perspectives become important in the interpretation of breakdown of the self, as well as sensorial or bodily symptoms, of research subjects.

CHAPTER 5

Theoretical Perspectives: Schizophrenia, Power and Social Structure

Having dealt with identity, illness and schizophrenia, it remains to be seen how these issues relate to broader questions of power and social structure. How may we theorise the relations of power that surround and enmesh the person diagnosed with schizophrenia? Perhaps the most logical place to start is with the historical accounts of power in asylums and hospitals that we find in the work of Michel Foucault (1977, 1988) and Erving Goffman (1961). These accounts form part of the canon of twentieth century social theory and have influenced the way in which we understand the operation of social power in general. As interesting and important as these accounts are, however, they have to a large extent been superseded by processes of deinstitutionalisation and developments in psychopharmacology discussed later in the chapter. The same may be said about the thesis that psychiatry is essentially a discipline of social control. To help move beyond these frameworks and develop a more adequate account of psychiatric power in the contemporary moment, the chapter focuses on the work of Michel Foucault and Nikolas Rose. Whilst a significant part of Foucault's work deals with the asylum as disciplinary institution, there are aspects of his writings that can help us theorise a deinstitutionalised environment for mental health care. In particular, Foucault's analysis of the relationship between "truth" and "power", along with his understanding of the productive nature of power shed some light on the relationships of power a person diagnosed with schizophrenia may encounter when meeting with mental health workers or when visiting a psychiatrist. Rose's discussion of service provision in neoliberal states is also relevant, as are his explorations of the development of neurological science and, even, the emergence of a neurochemical self. Finally, accounts of the deinstitutionalisation of the mentally ill and of the

growing power of psychopharmaceutical companies round out our theorisation of relations of power and structure that surround the person diagnosed with schizophrenia.

Power, Asylums and Hospitalisation

Hospitalisation has, in the past, formed a significant part of the experience of schizophrenia. Sufferers were often detained for significant periods, if not for life. As such, the analysis here of power and social structure affecting people diagnosed with schizophrenia begins with an account of power, asylums and hospitalisation. As a general comment, we may say that conditions in such asylums, as well as hospitals and wards, often tended towards the inhumane. The asylum would often become the life of the sufferer; he or she would become institutionalised. The contributions of the “anti-psychiatrists” such as Szasz (1974; 1997; Cf. Vatz and Weinberg, 1983; Bentall, 2004; Fulford, 2004), as well as depictions in popular culture such as the film *One Flew Over the Cuckoo’s Nest*, have pointed out the more callous aspects of the asylum/hospitalisation system (see Gabbard and Gabbard, 1992). However, *contemporary* psychiatric practice has tended towards radically reducing the time spent hospitalised and, under the policy of deinstitutionalisation, emphasised treatment in the community.

The definitive historical account of the impact of hospitalisation upon people with mental illness is given by Goffman in *Asylums* (1961). In this text, Goffman describes mental asylums (as they were at the time of writing) as “total institutions” (although, cf. McEwen 1980). A total institution is one where:

Their encompassing or total character is symbolized by the barrier to social intercourse with the outside and to departure that is often built right into the physical plant, such as locked doors, high walls, barbed wire, cliffs, water, forests or moors (1961, p. 4).

To further elaborate, the total institution is one where all “aspects of life” (1961, p. 6) are controlled, scheduled and regulated by a central authority. Communication and mobility between “inmates”

and “staff” is generally strictly controlled with “forced deference patterns” (1961, p. 22). The psychiatric subject typically becomes institutionalised, adopting the rhythms and structures of asylum life, as well as the relations of power within the asylum, as their own. “He begins some radical shifts in his *moral career*, a career composed of the progressive changes that occur in the beliefs that he has concerning himself and significant others” (1961, p. 14). A “privilege” system develops for “good behaviour”. “Obedience tests” and “will-breaking contests” by staff are common, as is inmate demoralisation (1961, p. 11) and processes described as “mortification of the self” where the inmate is stripped of personal belongings and other items of interest to his or herself (1961, p. 28). Goffman describes a number of “tacks” an inmate can follow in response to the environment of the total institution:

- “situational withdrawal” (where the inmate withdraws into the limited realm of their personal environment);
- the “intransigent line” (where the inmate challenges the institution);
- “colonization” (where the inmate attempts to make as comfortable a living as possible in the institution); and,
- “conversion” (where the inmate adopts the official view of him or herself and attempts to play the role of the “perfect inmate”) (1961, p. 61-63).

Interestingly, Goffman describes “confession” (1961, p. 32) as a process often performed between patients and those in power at the asylum; interesting because it chimes with Foucault’s discussion of confession as an exercise of power between the psychiatrist and patient, considered below.

It is important to note that many of the more pernicious traits of the total institution have been lessened or removed in the contemporary Australian mental health system characterised by deinstitutionalisation. Even the term “asylum” has been replaced by “hospital”, “ward” or “clinic”. In such a climate, the power exerted by the mental health apparatus is more spread out, more networked, less invasive (see Rudge and Morse, 2004). The term “negotiated power networks” is suggested later in Chapter 9 to account for the exertion of these relatively new kinds of power. With that said, hospitalisation, at least for a short while, still does occur in many cases of schizophrenia, and in some cases, lengthy stays in hospitals, wards or clinics do occur and affect ill people’s

subjectivity (Townsend, 1976). As such, the experience of power and hospitalisation is still worth examining further.

On the issue of power exercised in and through hospitals, Harding et al. (1997) argue that hospitalisation may cause “institutionalisation” of patients, even in a more contemporary situation where hospitalisation is shortened. Patients adopt a “good patient” role, including “to be dull, harmless, and inconspicuous; to evade responsibility, minimize stress, ignore others, to retain the right to behave unpredictably and have a certain ‘diplomatic immunity’ with staff” (1997, p. 58). In a more historical than contemporary account, Strauss et al. complement their discussion of illness trajectory (considered above) with a discussion of the impact that relationships and work within hospitals may have on the well-being of patients. Patients are often knowledgeable about the interplay between regimen technologies and their own unique body reactions; they frequently “become very skilled in managing those reactions” (Strauss et al. 1989, p. 128). Strauss et al. recognise “patient work” as largely unrecognised, often invisible, work done by patients during their own care. Such work is described as “trajectory work, in the service of managing and shaping aspects of their trajectories” (Strauss et al, 1989, p. 134). Staff expectations of patients may become important – staff may “cajole, tease, scold, empathize, but insist on obedience... Alternatively the staff may attempt to negotiate”, or ultimately engage in building a negative reputation around the subject (Strauss et al, 1989, p. 130). These processes would seem vital to experiences of power within the social structure of the hospital.

However, the mental health sector in NSW is today a deinstitutionalised one, and many people diagnosed with schizophrenia will generally not spend enough time in a hospital or clinic to become fully institutionalised. Rather, they are more likely to live with family, or alone, in houses or apartments. This research finds that many such people live alone, regularly seeing a psychiatrist or

mental health social worker, sometimes with tenuous links to family members. More on deinstitutionalisation is said below.

Strauss et al. also treat issues of hospitalisation, emphasising that through institutionalisation at the time of writing, patients may be taught vital skills, but that “the teaching perspective often focused too narrowly on the medical, technological, and procedural aspects of illness management, omitting or underplaying important sociopsychological and biographical aspects of chronic illness trajectory management” (Strauss et al, 1989, p. 140). Sociopsychological aspects of chronic illness trajectory such as negotiating the doctor/patient relationship, navigating the influence of psychopharmacology (Seale et al., 2006) and managing both life and illness issues would seem significant here. Finally, Strauss et al. observe that “chronic illness trajectories flow from home residence into and through hospitals, and out again back to the home”. This flow to the home picks up upon the theme of deinstitutionalisation met in Chapter 6, 7, 8 and 9.

Roe makes a further contribution to our understanding of self and the social structure of the hospital or clinic, whilst recognising that hospitalisation is not as ubiquitous as it was in the past. In his thesis regarding the relationship between self and the illness trajectory of people suffering psychosis, Roe argues that patients may feel passive, or confronted, in mental institutions (1997, p. 106). This observation differs from most people with chronic illness who may find themselves in regular hospitals where the stigma of mental hospitalisation may not apply, or may have been released and deinstitutionalised. Chapters 6, 7 and 8 suggest that deinstitutionalisation, in part facilitated by developments in psychopharmacology, has de-emphasised the significance of the hospital experience and has created a new sense of passive social isolation amongst research respondents.

Beyond these writings, there lies space for future thought – for writing about how relations of power and social structure impact identity in people diagnosed with schizophrenia outside the hospital or

clinic. Issues of influence and negotiation, consensus and scheduling, agency and structure are all areas for examination in the context of the person diagnosed with schizophrenia. These important issues surrounding power, identity and schizophrenia are addressed below through the consideration of the work of Michel Foucault and Nikolas Rose, whilst the significance of social structure is addressed through an examination of the roles of social control, psychopharmacology and deinstitutionalisation.

The Social Control Thesis

There lies a strain of thought that sees psychiatry and the treatment of psychiatric patients, especially their carceral treatment, as a form of social control (Szasz, 1974; Horwitz, 1982; Cohen, 1985; Conrad, 1992). This is generally not a contemporary thesis, although it may have current counterparts. This perspective complements Goffman and Symbolic Interactionism by delving into the macro-social and institutional elements of the response to mental illness. According to the “social control” thesis, psychiatric patients are regarded as a threat to reason and ordered behaviour, and as such are controlled, through hospitalisation or drug regimens.

A cornerstone of the social control thesis is a recognition of the power of the psychiatrist. The psychiatrist is a medically trained and recognised figure who is typically the person who interrogates those designated with possible mental illness, identifies that illness as a known diagnosis, authorises treatment and, often, incarceration in a mental institution, and presides over continuous incarceration (Szasz, 1974; Cohen, 1985; Horwitz, 1982). Emily Wilson (2003, p. 66) argues that the relationship between psychiatrist and patient is one of power (Wilson, 2003, p. 66). Similarly, Willard Gaylin (1978, p. 2) argues that the psychiatric definition of normalcy acts as a coercive tool “beyond electrodes and surgical scalpels” (c.f. Tishelman and Sachs, 1998, p. 53). Furthermore, Healy (2002, p. 30) refers to Marcuse’s critique of the mental health establishment; Marcuse’s critique followed

the lines that the mental health establishment was “psychologizing alienation’, and profiting from this. However, Marcuse’s argument was one made in the 60s and 70s, and may have been superseded in a contemporary context. Nevertheless, all members of the Australian Schizophrenia Research Bank – the source of interviewees for this study – have been diagnosed by a psychiatrist, and so the criticism of power in the psychiatric apparatus is relevant to the analysis of power and influence in this thesis.

The social control critique points to the use of restrictive incarceration in mental institutions, often accompanied by such treatments as insulin coma, electro-shock therapy, lobotomy and restriction of movements and personal freedoms, as evidence of the repressive force of psychiatry (Miller and Rose, 1985, p. 3; although lobotomy and insulin coma have all but disappeared in contemporary clinics). The social control thesis typically sees psychiatry as a discipline which acts alongside criminal justice, the welfare state and policing to control people whose behaviour is disturbing to the wider society (Hayne, 2001, p. 27; Szasz, 1974; Cohen, 1985; Talley and Coleman, 1992; Crowley-Cyr 2005). Indeed, some have argued that the labelling of mental illness serves the explicit purpose of controlling the behavior of non-conforming members of society (Sarbin and Mancuso, 1980). In a similar vein, Moncrieff (2010) argues that psychiatric diagnosis functions in fact as a political device to justify the social control of behaviour that threatens the social order. Behavioural and experiential phenomena, from insanity to sadness, become the often exclusive interest of psychiatry – pathologising aspects of the human condition (Miller, 1986, p. 15). Indeed, the discipline has been understood in the past as a branch or arm of the state (Cohen and Scull, 1983) and was often disguised as humanitarian policy (Scull, 1983; cf. Prilleltensky, 1990).

Allan Horwitz (1982) offers a thorough, though perhaps dated, account of the social control of mental illness. Essentially Horwitz envisions psychiatry as an apparatus for social regulation through “therapeutic control”. More specifically, psychiatry normalises certain behaviours and thoughts.

Those designated abnormal enter the psychiatric system, where they are diagnosed, labelled, incarcerated and monitored; their disorder ordered and given meaning (Horwitz, 1982, p. 121-122). Horwitz also interrogates the intersection between the diagnosis of mental illness and such social characteristics as class, ethnicity, culture and gender; as well as communal and individualistic societies. This intersection reveals different attitudes towards, and likeliness of commitment, to mental institutions, suggesting both that the recognition of mental illness is socially contingent and that treatments vary with social situation. Horwitz emphasises psychotherapeutic treatments such as psychoanalysis, and dismisses psychopharmacology as a nascent form of social control (see Brown, 1985b, for a discussion of the uptake of psychoactive drugs in the US). Nevertheless, we may perhaps extend Horwitz's analysis to see the prescription and encouragement to take drugs with a behavioural and psychotropic effect as an expanded form of social control. The emphasis on power and social control again complements the interests of this thesis, and is analysed further in Chapter 9.

The common criticism of the social control thesis is that it does not take account of advances in contemporary psychopharmacology which may have replaced many offensive mental treatment practices, and fails to recognise the deinstitutionalisation of previously carceral mental institutions. Both of these changes would seem to weaken the structure of power relations – or create more subtle power relationships – between psychiatrists and the mentally ill. These issues are considered below, and inform the research carried out for this thesis. The position is also overly deterministic, not recognising agency exercised by patients. Nevertheless, we must remain aware of the elements of social control that exist in relation to particularly difficult or disturbed (or disturbing) patients, as seen at certain points in the upcoming Results Chapters.

Michel Foucault

The work of historian Michel Foucault focuses on many of the same themes of psychiatry, power and institutionalisation but in many ways, Foucault offers a more subtle analysis of power and identity than those proposing the social control thesis. Foucault's work on power and identity is complex, and deserves close scrutiny.

Early in his career, Foucault turned his attention to the treatment of the mentally ill, resulting in the text *Madness and Civilization* (1988). This work had two purposes. The first was to offer a detailed and critical historical account of the incarceration of the mentally ill in the 18th century in France, where incarceration was understood as a new and promising development in the treatment of the mentally ill. Largely on the basis of this history, Foucault has been described as a member of the anti-psychiatry movement (although Foucault (2001, p. 243) responded strongly against this characterisation). The second purpose was to draw a broader picture of the relationship between madness and rationality at the cultural level. Foucault argues that the designation and incarceration of the "mad" was a necessary correlative of the emergence of concepts of "rationality" or "reason" in the wider culture. Reason, in its own way, created madness and labelled it as "mental illness" as a means of control. Certainly Foucault's conception of the cultural inter-relation between madness and rationality is an interesting suggestion, though probably not one that bears strongly on identity formation in individual people diagnosed with schizophrenic. In any case, this aspect of Foucault's work does not account for the rise of psycho-pharmaceuticals and deinstitutionalisation, and so do not bear directly on the issues at hand in this thesis.

Foucault's academic project, through many works, is complex and multifaceted. One of his overriding concerns has been to explore the forms of power that had not been adequately theorised at times of writing; and which implicitly produce the subject – "[s]ubjects are discursively produced by

particular historical power relations” (Cooklin, 2004, p. 11). Foucault’s interest is in decentred networks of power that exist through human sciences such as psychology, criminology, sociology, political economy, social work and, of course, psychiatry (Foucault, 2001; 2006; Gordon 1980); human sciences that effectively produce the modern subject. It is Foucault’s task to write a history of power without a “transcendental subject”. This analysis of power is more detailed and goes further into the institutional, professional and academic sources of identity than the symbolic interactionist and social control theses considered so far.

Foucault’s analysis of power is extended in his text *Discipline and Punish* (1977) to common forms of institutions – namely, for our purposes, hospitals and asylums. In these institutions, particular forms of “discipline” occur. These include a “disciplinary” surveillance where members at the centre of power relations ensure self-censure by those at the edges of power called “panopticism”. Further techniques include apparatuses of power such as timed interactions, testing and analysis of those at the edges. In his conclusion to this book, Foucault argues that a “disciplinary society” has emerged; thus we may see discipline as a form of social control. This is a question we will explore further in Chapter 9, that is, whether a form discipline is exerted by patients who do *not* abide in the institutions of clinics or hospitals, where panopticism takes place.

Furthermore, Foucault has emphasised the circulation of power exercised through a network-like organisation, never localised, never “in anybody’s hands” nor appropriated as wealth (Foucault, 1980, p. 98; 1982). Clearly the form of psychiatry that diagnoses and medicates schizophrenia, creating a “medical patient” identity involves the exercise of such power between psychiatrist and patient. Indeed, we may read deinstitutionalisation (considered further below) as part of a de-centred network of power.

The second point we may make about Foucault's project is his insistence that schemes of knowledge in the human sciences, emerging in "discourses", are inextricably linked, in multiple and strategic fashions, with the effects of power. Foucault states that "the exercise, production, and accumulation of knowledge cannot be dissociated from the power mechanisms with which they maintain complex relations that must be analysed" (2001:291). The discipline of psychiatry and its interactions with people with schizophrenia is no exception to the principle of power/knowledge. The discipline of psychiatry can be understood as the entire apparatus of psychiatric offices, procedures, training, professional representation, structure of interview, diagnosis, and control of post-diagnostic institutionalisations; all reinforcing the significance of psychiatric power/knowledge and, in doing so, forming the identity of the mental patient. In this context, it is also apposite to briefly consider Foucault's concept of truth. In a move that has often led to the accusation of postmodernity or poststructuralism in Foucault's project, Foucault rejects the idea of referentiality as a basis of truth, and instead interrogates the way truth is bound up in forms of power/knowledge "as a system of ordered procedures for the production, regulation, distribution, circulation and operation of statements" (Foucault, 1980, p. 133). "Truth" is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extend it." (Foucault 1980, p. 133). Thus the truth of a diagnosis of schizophrenia, which may have significant impact on the subject's identity, is intimately tied up with the "production, regulation, distribution, circulation and operation of statements" about the patient's behaviour, brain or mind.

The third point we may highlight about Foucault's project is his assertion that the exercise of power/knowledge is not strictly negative; it can be *productive* of certain states of being (Foucault, 1980, p. 119; C.f. Foucault, 1997, p. 87). For example, the exercise of panoptic power in the prison may encourage prisoners to reform their own behaviour; the exercise of governmental power may release the dynamic potential of a populace. This emphasis on the productive nature of power has interesting ramifications in the theorisation of the diagnosis of schizophrenia and the production of

post-diagnostic identities. The interaction with the psychiatric apparatus is “productive” in the sense that it produces a patient, or person in the “sick role’, who subsequently can enter mental health facilities to interact with recuperative mental health structures and, of course, use psychopharmaceutical agents.

We have seen the concepts of power/knowledge, truth and discourse and have related them to practices of psychiatric diagnosis and identity. Central to the functioning of these concepts is the “structure of diagnosis” – the recurrent patterns of interaction, interview, questioning and identification of a possible diagnosis. There is a clear structure of diagnosis whereby one person reveals the “inner truth” of their psyche (internal identity) through speech, and this truth is transformed into a diagnosis of schizophrenia, eventually leading to hospitalisation, treatment and post-diagnostic identity formation and maintenance.

Again, we may look to Foucault’s work to understand the structure of diagnosis. Clearly we may draw on the threads of analysis here posed to discuss the structure of the psychiatric diagnosis:

The [medico-clinical] examination of the fixing, at once ritual and “scientific’, of individual differences... clearly indicates the appearance of a new modality of power in which each individual receives as his status his own individuality... the examination is at the centre of the procedures that constitute the individual as effect and object of power, as effect and object of knowledge. With it are ritualised those disciplines that may be characterised in a word by saying that they are a modality of power for which individual difference is relevant. (Foucault, 1977, p. 192).

More specifically we may refer to Foucault’s discussion of “confession” as a fundamental structure in Western societies used to produce power around subjects (and produce subjects through power).

Confession is described as “one of the West’s most highly valued techniques for producing truth”, a technique that has emerged not only in religion, but also in justice, medicine, education, family and love relations; “one confesses one’s crime, one’s sins, one’s thoughts and desires, one’s illnesses and troubles; one goes about telling, with the greatest precision, whatever is most difficult to tell”

(Foucault, 1998, p. 59). Foucault explicitly recognises that psychoanalysis grew out of confessional procedures (Foucault, 1980, p. 191). Although the practice of contemporary psychiatry may no

longer be seen as psychoanalytic, instead as pharmaceutical-focused, it is clear that the current structure of psychiatric diagnosis resonates with Foucault's concept of confession, and such confession can form the basis of identity formation.

Foucault's work offers a number of lenses through which we may examine power and the formation of identity in people diagnosed with schizophrenia. The structure and power of the psychiatric discourse, embedded in psychiatric institutions – the psychiatric apparatus – offers a clear backdrop against which the person is inducted into the role of patient. Insofar as Foucault analyses this apparatus and discourse, he is moving beyond the symbolic interactionist position and is offering a more subtle analysis of power than in the social control thesis. The discourse of psychiatry, psychopharmacology and relations between the psychiatric body all emerge as the conduit through which the network of power is exercised not merely over but also through the patient's identity. In many ways this power may also be conceived as productive, insofar as it produces a subject who is ready for hospitalisation and treatment.

There is an important criticism of Foucault's oeuvre we should consider. That is, Foucault's work generally has difficulty theoretically accommodating the expression of agency by subjects of power (Cooklin, 2004; Kachra, 2006). In the structure/agency relationship, he seems firmly connected to structure through discourse and institutions. The subject, with its agency, has disappeared. Such a criticism relates strongly to Cooklin's comment that "there is nothing nondiscursive" (2004, p. 16; c.f. 2004, p. 62) left in Foucault's theorisation of power/knowledge and society. One implication of this emphasis on discourse and blindness towards agency is that Foucault does not provide a basis from which the "subject" may be "liberated" or "freed" from a relation of power. Each such move towards liberation is really a movement into a different formation of power. There is no potential of "freeing subjugated discourses". On the other hand, Lemke (2011) offers a reading of Foucault that emphasises "critique as ethos" (Lemke, 2011, p. 38) as an emergent feature in Foucault's later work;

here the self is engaged in “permanent critique” (Lemke, 2011, p. 39) of its socio-political and ethical situation. In particular, Lemke refers to “desubjectivation” as a move that “represents an integral part and a visible sign of the ethical self-formation that is characterised by a peculiar symmetry of means and ends” (Lemke, 2011, p. 37). Such a move helps make sense of the fact that while Foucault dedicated himself to a number of political causes during his life; he did not advocate political “solutions” to problems of power in his writing, aside from critique (this issue is discussed in Kachra, 2006, p. 13-14). This difficulty around the concept of agency is further considered in Chapter 9.

One solution to the agency problem is to emphasise the concept of “resistance” that Foucault develops in his work *The Will to Knowledge: History of Sexuality Volume 1* (1998). Foucault argues that all exercises of power naturally involve the existence of resistance to that power. He writes that the exercise of power:

depends on a multiplicity of points of resistance: these play the role of adversary, target, support, or handle in power relations. These points of resistance are present everywhere in the power network (1998, p. 95).

This concept of resistance may be useful in understanding the diagnosis and rebuilding of post-diagnostic identities. It can help us understand such phenomena as non-insightful behaviour, “acting up” in psychiatric care facilities, or eluding complete confession to one’s psychiatrist, that is to say, what appear to be exercises of agency against power. However, Foucault goes on to argue that resistance is no great program for revolt – it is dispersed and capillary:

[T]here is no single locus of great Refusal, no soul of revolt, source of all rebellions, or pure law of the revolutionary. Instead there is a plurality of resistances, each of them a special case... [B]y definition, they can only exist in the strategic field of power relations (1998; 95-96).

The second point made here, that resistance can “only exist in the strategic field of power relations”, is important. This point establishes that, although resistance may appear to be an exercise of agency, it is really still wholly implicated in the relations of power that Foucault analyses. The subject is not a free, self-determining agent. The problem of agency still remains.

There is another possible solution to the problem of agency. In his texts *The Use of Pleasure: The History of Sexuality Volume 2* (1992) and *The Care of the Self: The History of Sexuality Volume 3* (1990) (C.f., Cooklin, 2004, p. 100), Foucault explores elements of male sexuality in Greek society in the fourth century BC and ancient Roman society in the second century AD. In particular he depicts an “aesthetic” and “ethics” of the self. In these texts Foucault is interested in how a historically singular experience of sexuality is constituted by “the forms within which individuals are able, are obliged, to recognize themselves as subjects of this sexuality” (1992, p. 6). His central task is:

to analyze the practices by which individuals were led to focus their attention on themselves, to decipher, recognize, and acknowledge themselves as subjects of desire, bringing into play between themselves and themselves a certain relationship that allows them to discover, in desire, the truth of their being, be it natural or fallen. In short, with this genealogy the idea was to investigate how individuals were led to practice, on themselves and on others, a hermeneutics of desire, a hermeneutics of which their sexual behavior was doubtless the occasion, but certainly not the exclusive domain (1992, p. 5).

The moral dimension in this analysis was paramount: “[H]ow, why, and in what forms was sexuality constituted as a moral domain?” (1992, p. 10). The aesthetic of self-transformation was also important; Foucault writes of: “[T]hose intentional and voluntary actions by which men not only set themselves rules of conduct, but also seek to transform themselves, to change themselves in their singular being, and to make their life into an *oeuvre* that carries certain aesthetic values and meets certain stylistic criteria” (1992, p. 13). This aesthetic involves privileged Greek male subjects and Roman male subjects actively shaping their own bodies and sexual life through self-control, balance and self-command. Foucault describes a moral practice in Ancient Greece that: “requires [the subject] to act upon himself, to monitor, test, improve, and transform himself” (1992, p. 28). In Greece, such action required monitoring and acting upon love, diet, household economy and governing the family, relationships, and erotic life with boys and women. In Rome, such action required dream analysis, the “cultivation of the self”, an ethic of relating to others, exercising and taking care of the body, changes in martial roles, and sexual relationships with boys. The cultivation of the self:

can be briefly characterized by the fact that... the art of existence – the *techni tou biou* in its different forms – is dominated by the principle that says one must “take care of oneself”. It is this principle of

the care of the self that establishes its necessity, presides over its development, and organizes its practice (1990, p. 43).

Interestingly, in Greek culture, the care of the self is in close correlation with medical thought and practice (1990, p. 54). In the contemporary context, “care of the self” has been invoked as a tool in the analysis of illness narratives (Frank, 1998).

The significance of this form of activity for the problem of agency (and for Foucault’s broader project of erasing the subject) is that it involves an active subject exerting power over himself – the self has become partially detached from relations of power and can exercise certain forms of power independently of these relations. However, although this development in Foucault’s work may provide a gap through which agency may appear, we must still establish whether the temperance of personal male sexuality in ancient Greece and Rome relates directly to the actions of people diagnosed with schizophrenia. This theme is explored in Chapter 9.

We may also criticise Foucault in relation to the current project. Although his analysis of power, particularly in *Discipline and Punish* is subtle and convincing, it was written at a time before deinstitutionalisation had emerged as a significant phenomenon in the treatment of mental illness. We may regard Foucault’s emphasis on decentred power as a precursor to deinstitutionalisation, but Foucault’s analysis is largely limited to the institutional level of the hospital or clinic. New forms of power seem to be circulating. These are explored further in Chapter 9. Foucault’s analysis was also developed at a time before psycho-pharmaceuticals that are effective for psychosis were in common use. We now live in an environment where psycho-pharmaceuticals have dominated (some may say colonised) treatment and understanding of schizophrenia, and a clinical landscape reformed by the movement towards deinstitutionalisation.

Nikolas Rose

Nikolas Rose uses some of the conceptual tools provided by Foucault in order to trace relationships between “governmentality”, health and identity. Governmentality may be understood as a concept seeking to “draw attention to a certain way of thinking and acting embodied in all those attempts to know and govern the wealth, health and happiness of populations” (Rose and Miller, 1992, p. 174).

In his article (1996b) “Governing “Advanced” Liberal Democracies”, Rose traces the “strategies, technologies, programmes [and] techniques” (Barry et al, 1996, p. 4) that have emerged as governmentality under “advanced liberal” democracies for the governance of citizens (Cf. Carpenter, 2000). The term advanced liberal democracies may be used interchangeably with “neoliberal” democracies or democracies in a state of “advanced” or “late” capitalism. Rose argues:

Paradoxically, neo-liberalism, alongside its critique of the deadening consequences of the “intrusion of the state” into the life of the individual, has none the less provoked the invention and/or deployment of a whole array of organizational forms and technical methods in order to extend the field within which a certain kind of economic freedom might be practised in the form of personal autonomy, enterprise and choice (1996b: 10).

Rose argues that liberal democracies typically followed strategies of government involving new practices that sought to “shape and regulate individuality”; most relevantly through discipline in the “lunatic asylum” where people will come to “govern themselves, master themselves, care for themselves” (Rose, 1996b: 45; Cf. Sawyer, 2005). Such a picture clearly evokes Foucault’s discussion of the “cultivation” or “care of the self”.

Rose’s discussion of government in advanced liberal democracies begins with the claim that:

In the name of social *and* personal wellbeing, a complex apparatus of health and therapeutics has been assembled, concerned with the management of the individual and social body as a vital national resource, and the management of “problems of living”, made up of techniques of advice and guidance, medics, clinics, guides and counsellors (1996b: 37).

Clearly people diagnosed with schizophrenia will come into contact with such advice and guidance, medics, clinics, guides and counsellors. Rose continues:

Advanced liberal rule depends upon expertise in a different way, and connects experts differently into the technologies of rule. It seeks to degovernmentalize the State and to de-statize practices of

government, to detach the substantive authority of expertise from the apparatuses of political rule, relocating experts within a market governed by the rationalities of competition, accountability and consumer demand... Individuals are to be governed through their freedom, but neither as isolated atoms of classical political economy, nor as citizens of society, but as members of heterogeneous communities of allegiance, as “community” emerges as a new way of conceptualizing and administering moral relations amongst persons (1996b: 41).

There are two aspects of this quote that are relevant to the discussion at hand. The first concerns the “relocating” of experts within a market.

In place of collective provision and social solidarity the new rationality of government proposes notions of security provided through the private purchase of insurance schemes, health care purchased by individuals and provided by the health industry, housing offered through the private sector and efficiency secured through the discipline of competition within the market (Rose and Miller, 1992, p. 200).

(It is an interesting aside that Rose and Miller use the term “discipline” here, loaded as it is in Foucauldian discourse as the name of power exercised in prisons, hospitals, schools and so forth.)

Such relocation and the emergence of a market in mental health occurred to some extent in the Australian mental health sector with the emergence of a for-profit “psychopharmaceutical complex” (Healy, 2002, p. 368; Kovel, 1987, p. 346; C.f. Richmond and Savy, 2005 for use of the similar term “psychiatric industrial complex”). This term describes the relationship between psychopharmacology, psychiatry, researchers, government, the legal system and consumers. The term deliberately echoes the expression “military industrial complex” to describe the complex ways elements of systems affecting mental illness interact and how they have come to be beholden to financial and industrial concerns (Healy, 2002, p. 2).

However, whilst the psychopharmaceutical complex exercises considerable market power in Australia, Australia still provides a mixed public/private system of health services; the socialisation of health, including Medicare rebates for psychiatrists, subsidised psychiatric hospital wards and the Pharmaceutical Benefits Scheme, remains a bulwark against completely market-oriented health services. We may take a small detour at this point to briefly characterise mental health services in NSW and Australia. Contemporary mental health services in NSW are largely government funded, and available freely to the public, although a substantial system of private health insurance, and

private psychiatrists and clinics, complements the public system. Present-day public mental health services focus on high-intensity mental health services in clinics, with the majority of subsequent service use focused on community care (Ash et. Al, 2012). This structure has its genesis in the movement towards deinstitutionalisation, discussed later in this Chapter. Whilst considerable amounts of money are currently spent by Federal and State/Territory governments in the public mental health system, at the time of writing the system is in a state of flux and considerable reform is being suggested by peak bodies (National Mental Health Commission, 2014; Mental Health Australia, 2015).

As we have seen, mental health services in Australia, even if in need of reform, retain a strong public character. However, this emphasis on public service provision may be undercut, to some extent, by the language that is commonly used around severe mental health. Specifically, the ongoing use of the term “consumer” that has been suggested by some mental health support groups, instead of more stigmatised terms such as “mentally ill person” or “schizophrenic”, is tied closely to a market conception of mental health treatment. In a mental health service market, presumably those without market power (MacLAughlin 2009) – people with less money or less mobility, as many people diagnosed with schizophrenia are – suffer (Cf. Holdsworth et al, 2004). Furthermore, the cost-based arguments made for for deinstitutionalisation reflect the influence of market-based governmentality.

The second aspect of the Rose quote is the emergence of “community” as the “new way of conceptualizing” the subjects of governance (for a discussion of the rise of “community” as the subject of advanced liberal governance see Rose, 1996c). In the Australian context, such community is built up in a deinstitutionalised environment, not only by a relatively independent psychiatric apparatus, its service workers, and its patients, but also by semi-independent and independent support organisations and groups set up to facilitate interaction amongst people with schizophrenia.

Experts and treatment organisations are “de-statized” – “a form of government through shaping the powers and wills of autonomous entities: enterprises, organizations, communities, professionals, individuals” (1996b, 56; Cf. Rose 2006; Rose and Miller 1992). Rose and Abi-Rached write in *Neuro:*

The New Brain Sciences and the Management of the Mind:

A new configuration of sites for the practice of psychiatry was taking shape, together with their populations – halfway houses; residential homes; specialized units for children, alcoholics, anorexics, or drug users; and clinics of many different sorts (2013, p. 123).

The voice of the patient...

presaged the emergence of psychiatric users into the mainstream of debates about psychiatry and mental health, with narratives of illness and recovery, pressure groups, and support networks playing an increasing role in psychiatric politics (2013, p. 123).

Professionals can exercise their expertise “at a distance” from the central state (Rose and Miller 1992, p. 184). Indeed, Rose writes that “[e]xperts have the capacity to generate what we term *enclosures*: relatively bounded locales or types of judgment within which their power and authority is concentrated, intensified and defended” (Rose and Miller, 1992, p. 188). Clearly the psychiatric apparatus is such an enclosure.

The advanced liberal agenda discussed by Rose also includes an attack on entitlement-focused conceptions of welfare, preferring in its stead market mechanisms, as well as quasi-autonomous and autonomous organisations to provide for the welfare of individuals (see Rose and Miller, 1992, p. 198-199; cf. Muetzelfeldt, 1999). The use of such mechanisms and organisations clearly moves beyond the traditional distinction drawn in some political philosophy between the state and civil society; the state and non-state. Such distinctions are blurred (Rose, 1992):

[The] political vocabulary structured by oppositions between state and civil society, public and private, government and market, coercion and consent, sovereignty and autonomy and the like, does not adequately characterize the diverse ways in which rule is exercised in advanced liberal democracies... Personal autonomy is not the antithesis of political power, but a key term in its exercise, the more so because most individuals are not merely the subject of power but play a part in its operations (1992, p. 174).

This focus on the blurring of coercion and consent becomes important in Chapters 6, 7, 8 and 9, where the negotiated relationships between people diagnosed with schizophrenia and the psychiatric apparatus are discussed.

At the individual level in advanced democracies, people are encouraged to “reconceptualise themselves in terms of their own will to be healthy, to enjoy a maximized normality” (1996b: 52). Later, Rose refers to people becoming “experts of themselves” (1996b: 59) – encouraged “to adopt an educated and knowledgeable relation of self-care in respect of their bodies, their minds, their forms of conduct and that of the members of their own families” (1996b: 59). Such a description again recalls Foucault’s concept of “cultivation” or “care of the self”. The reconceptualisation involved here would clearly appear to be problematic for many people diagnosed with schizophrenia, where, typically, the person finds him or herself trapped in a psychological cage with their sense of self compromised and with little ability to live a normal life, let alone “enjoy a maximised normality”. Indeed, as seen in Chapter 6, many of the respondents in this study suffered a breakdown or disruption of personal identity that would preclude adopting an “educated and knowledgeable relation of self-care in respect of their bodies, their minds, their forms of conduct”. Furthermore, in a number of cases, the relationship with family members had become strained, again reducing the ability to “adopt [a]... relation of self-care in respect of... the members of their own families”.

Rose makes a further contribution to the understanding of power, identity and schizophrenia with his concept of the “neurochemical self” (Rose, 2003; 2007, p. 187-223; c.f. Rose and Abi-Rached, 2013). In the context of a discussion about biology, identity and power, and drawing on Foucault’s work in *The Birth of the Clinic* (2003; Abi-Rached and Rose 2010), Rose explores the proposition that advances in neurobiological sciences and medicine have heralded the emergence of a new way of thinking about the self – a “neurochemical self”:

I suggest that a neurochemical sense of ourselves is increasingly being layered onto other, older senses of the self, and invoked in particular settings and encounters with significant consequences. Individuals themselves and their authorities... are beginning to recode variations in moods, emotions, desires, and thoughts in terms of the functioning of their brain chemicals, and to act upon themselves in the light of this belief (2007, p. 222-223; C.f. Rose, 2003).

Put differently:

In our biologized culture, not merely the sicknesses of human beings, but also their personalities, capacities, passions, and the forces that mobilize them – their “identities” themselves – appear to be explicable, potentially at least, in biological terms (2007, p. 225).

In the context of mental illness “[c]linical observations on the effective treatment of patients with biological remedies – notably the results of giving chlorpromazine to psychotic patients – together with the psychopharmaceutical discoveries of the 1950s” have led to a new conception of the brain and functional/structural changes accompanying mental illness (Rose, 2007, p. 189; Cf. Lewis and Volk, 2009). Rose also links the development of such psychopharmaceutical discoveries to the market for mental health products and the shaping of the psychiatric apparatus:

Today [mental disorders] are vital opportunities for the creation of private property and national economic growth. Indeed the profit to be made from promising effective treatment has become a prime motive in generating what counts for our knowledge of mental disorders (2007, p. 209).

The concept of the neurochemical self may have appeal for the friends and family of people diagnosed with schizophrenia, as well as sufferers themselves, insofar as a biological or genetic explanation of schizophrenia may reduce the sense of guilt felt, and divest responsibility, for the formation of this mental illness (Rose, 2007, p. 218). Rose also argues that a genetic explanation for the illness may serve to reduce stigma (Rose, 2007, p. 216). However, the concept of a neurochemical self may present a reductionist and limited approach to the understanding of schizophrenia and the process by which a sense of self is rebuilt and stabilised after a diagnosis. To some extent, such a critique is addressed by Rose and Abi-Rached when they argue both that the neurochemical self involves a significant degree of social shaping and plasticity, and that the neurochemical perspective does not replace philosophical, psychological, historical and sociological conceptions of self-hood, but complements them:

[T]he emerging neuroscientific understandings of selfhood are unlikely to efface modern human beings’ understanding of themselves as persons equipped with deep interior worlds of mental states

that have a causal relation to our actions. Rather, they are likely to add a neurobiological dimension to our self-understanding and our practices of self-management (2013, p. 223).

The neurochemical self is thus one amongst many ways of understanding self-hood.

The Psychopharmaceutical Industry

This chapter now turns to the influence of the psychopharmaceutical industry and then of deinstitutionalisation¹⁵. The pharmaceutical industry for psychotropic medication in Western nations is both large and prominent, and exerts a strong political influence over psychiatry and the diagnostic process experienced by patients (Healy, 1993). The treatment of people with schizophrenia with psycho-pharmaceuticals bears great relevance to this thesis as it may help sufferers to understand their illness as originating in a neurochemical process, and insofar as successful medication can create the space for a certain reconstruction of identity. Pharmaceutical companies researching and selling psychiatric medication are described in this thesis as psychopharmaceutical companies, and the practice of these companies is described as psychopharmacology. Psychopharmaceutical companies may be defined as for-profit organisations that engage in applied research to develop new psychotropic medications for mental illnesses. Their focus is thus on the chemical intervention into states of mental illness. Psychopharmaceutical companies developing medical intervention for schizophrenia emerged in the United States in the 1950s, with later development of typical and atypical antipsychotic medication largely taking place after 1980. The psychopharmaceutical industry has effected what may be described as a partial colonisation of the psychiatric domain:

When it comes to the larger question of the choices that psychiatry makes, the extent to which the psychiatric mind has been colonized by the pharmaceutical industry is an increasing issue... The “hard” science’s input has come almost exclusively from pharmacology, and psychiatric thinking has accordingly become pharmacocentric (Healy, 2002, p. 387).

¹⁵ Note, the term “psychopharmacuetical industry” is used to specify one branch of pharmaceutical practice; many organisations in this industry also develop products of a non-psychoactive nature.

As we have noted, psychopharmacology focuses on developing, marketing and the sale of psychotropic medication. Rose writes on the topic of “bioeconomics” that:

[c]onducted at a molecular level, biology and medicine require long periods of investment, the purchase of expensive equipment, the maintenance of well-staffed laboratories, a multiplication of clinical trials, financial commitments for measures required to meet regulatory hurdles – in short, allocation of funds on a large scale over many years before achieving a return. Increasingly such investment comes from venture capital provided to private corporations, who also seek to raise funds on the stock market, and it is subject to all the exigencies of capitalization, such as the obligations of profit and the demands of shareholder value (2007, p. 31).

One of the significant consequences of this focus on the biological in research is that psychiatric illness comes to be understood as an essentially biochemical phenomenon, one where mental illness emerges as the result of the action of biochemical processes and structures within the brain; one where such illness can only be addressed through biochemical intervention. From this focus we come to a position where the mind itself (as well as epiphenomena variously described as the “self”, the “psyche”, the “personality”, and so forth), is understood as essentially biochemical in nature and structure. As Healy puts it, with neuroscientific advances “a bridge had been built between behaviour and neurochemistry.” (Healy, 2002, p. 106). The “new biomedical self” (Healy, 2002, p. 7) has arrived, and is explored in Chapter 9. There is clearly a connection here to Rose’s discussion of the “neurochemical self”, considered above.

The relationship between the neurochemical self and the interactive self of symbolic interactionism is complex. One approach is deterministic, the other recognises agency. On the one hand, we seem to have a conflict between a materialist and an interactionist conception of self-hood. On the other hand, we may also recognise that the very content of the neurochemical self – what constitutes a biomedical self – is communicated and made sense of in the context of symbolic interactions. In other words, the person experiencing biomedical self-hood understands the meaning of the self-hood in symbolic interactions with mental health workers and psychiatrists, all in the context of a society dependent on psychopharmaceuticals. Beyond these comments, perhaps it is enough to say that the essential disruption(s) of schizophrenia have a biological source, but the experience of

schizophrenia is one heavily influenced by social context, and it is this influence that interests us in this thesis.

Psychopharmacology requires specific or defined mental conditions that can be reliably identified so that precise medications can be given. To this end, the American Psychiatry Association prepared for the compilation of the DSM-III (the third Diagnostic Statistical Manual), a manual which describes each mental illness in specific terms that may be repeated by different doctors with high reliability, constituting psychiatry as a “biomedical/scientific discipline” (Gove, 2004, p. 365. C.f. Wilson, 1993 and Horwitz, 2002). With this in mind, it is important to link such formalisation to broader social structures such as a “transnational biomedical infrastructure that links knowledge, regulation, and the market – and which does so in different ways depending on divergent economic, institutional and professional contexts” (Lakoff, 2005, pp. 156-157). Medical insurance schemes, professional training practices, research and government regulation all have an interlinked role to play (Lakoff, 2005, p. 163), and all can have an impact on the person diagnosed with schizophrenia¹⁶.

The end result of these processes is that commercial psychopharmacology has, to a degree, colonised psychiatry. The market, operating in advanced liberalism as a tool of governance, is exerting influence over the psychiatric apparatus. As a result, we may be justified in using the term “psychopharmaceutical complex” This process has become so prevalent that American psychiatric practice has become or is becoming the norm in the treatment of aberrant behaviour throughout

¹⁶ There is a larger picture to all these impacts of psychopharmacology. The financial concerns of psychopharmaceutical practice have come to dominate elements of professional research and practice. Healy speaks to this subject, describing how even patient groups have been “transformed” by the “science” of psychopharmacology (Healy 2002, p. 217). And furthermore Healy emphasises relationships between medical communication and public relations agencies, where agencies often wrote drafts of articles in relevant journals and produced slides for speakers (Healy 2002, p. 311. C.f. Rennie 1999 and Huston and Moher 1996). We must not be blind to the fact these processes are essentially political. The following anecdote of a psychiatric symposium interrupted by protestors makes the point: “...During a symposium on clozapine [an effective antipsychotic with relatively severe side-effects] being held at an American Psychiatric Association meeting, demonstrators burst in and demanded that the drug be made available at a price that was affordable by patients who were not wealthy. The public pressure was intense. Government programs and some insurers refused to pay for the drug. But the company was unyielding. (Meltzer 1999).” (Healy 2002, p. 244).

the world (Watters, 2010). Lakoff (2005, p. 64) emphasises “internal” connections being drawn between “illness phenomenology, neurobiology and pharmaceutical indications”, that coexist with “external” connections between “globalization, money, publications, graduate training, the power of the American Psychiatric Association, [and] the prestige of the *American Journal of Psychiatry* – all push the American line” (Lakoff, 2005, p. 64). Indeed, just as psychopharmacology has colonised American psychiatric practice, so too is American psychiatric practice colonising global practices.

So, we have a picture of the psychopharmaceutical industry colonising psychiatric practice. But what is the significance of these developments for the issues at hand in this thesis? Perhaps the most important issue is that people with schizophrenia are likely to view their illness as originating in a neurochemical process, thus preventing feelings of guilt that they could have caused the disease themselves. The reconstruction of identity will proceed upon the assumption that they are undergoing a process dominated by the biochemical structure and function of the brain. To some extent, this assumption is reflected in the interviews analysed. Furthermore, people with the diagnosis will benefit in comparing their illness to other persistent physical illnesses. They may conceptualise themselves as “patients”. Indeed, taking anti-psychotic and related psychiatric medication may become part of the diagnosed person’s new identity; they may think of themselves as a medicated person. Finally, the successful medication of a schizophrenic complaint may create social space for an individual for identity reconstruction or rebuilding, and maintenance.

Deinstitutionalisation

The second significant social phenomenon affecting power and identity of people diagnosed with schizophrenia is deinstitutionalisation. The movement towards, and processes of, deinstitutionalisation in Australia echo those of the US and UK, although they generally occurred a few decades later (Pasamanick et al., 1967; Borus and Hatow, 1978; Freedman and Moran, 1984;

Morrissey, 1984; Sawyer, 2005). Laffey argues that leading to deinstitutionalisation, mental hospitals in Australia in the first half of the 20th century:

were overcrowded, treatment was desultory and piecemeal, and staff-patient relations were punitive and adversarial. Rates of long-term incarceration were high, filling hospitals with large numbers of “institutionalised” patients and absorbing staff time in the care of chronic cases (2003, p. 20).

Laffey also attributes the early elements of deinstitutionalisation in Australia to a concern with social psychiatry and the identity of patients – the “peculiar concerns of psychiatric patienthood” (2003, p. 22). However, he also argues that the activists from *National U*, a widely read student newspaper advocated psychiatric reform (Laffey, 2003, p. 27) and plots the results of the Australian psychiatric community absorbing the critiques of “liberation movements” which included “antipsychiatry, feminism and abortion, homosexuality, and pornography” (Laffey, 2003, p. 28). Unfortunately, there is not space here to present a thorough history of deinstitutionalisation in NSW¹⁷. Suffice to say, the positive impact of anti-psychotic drugs, both typical and atypical, left many patients diagnosed with schizophrenia in a position where they did not need to be constantly institutionalised (Gronfein, 1985). It is also likely that governments of the time perceived economic value in moving from a centralised, institutional system of care for patients towards a de-centralised, deinstitutional system of care where patients would see their psychiatrists relatively frequently and might be visited by mental health workers (Freedman and Moran, 1984; McClary et al., 1989; Harvey and Fielding, 2000). There may also be a relationship between broader cultural movements towards self-care and the movement for deinstitutionalisation (see generally Chamberlin, 1978 and Zigarus, 2004).

Despite these arguments in favour of deinstitutionalisation, it has also been argued that the backdrop to the movement of deinstitutionalisation and these processes was a general hostility

¹⁷ Unfortunately a complete and detailed history of deinstitutionalisation in NSW has not been yet written. “Overall... the lack of data on community mental health services around Australia is astonishing... [A] full understanding of the position facing sufferers of mental illness also needs to include data on employment, housing options and welfare arrangements. In summary, a comprehensive, evidence-based, evaluation of the desinstitutionalisation of mental health services in Australia is not possible at this time.” (Richmond and Savy 2005, p. 216. C.f.. Doessel 2009, p. 176). Also note that the history of deinstitutionalisation in Victoria has been written (Gerrand 2005a and 2005b), and the process in Victoria has been, in many ways, more successful than in New South Wales. See for historical context of deinstitutionalisation in Australia Stoller and Arcscott, 1955).

towards mentally ill people (Jaffey, 2003, p. 20; Cf, Chesters, 2005; Bigby and Fyffe, 2010; Minkoff, 1997. See Brown, 1985b, for an excellent discussion of deinstitutionalisation and its repercussions in the US. The complex structures of three-level, democratic, responsible government in Australia has often meant that instituting effective and integrated mental health policy can be difficult to achieve (See Grose, 1986 for a discussion of decommissioning a hospital). This results in lack of cross-sector coordination and lack of clear policy responsibility, limiting hope for suitable housing for people with psychiatric illness. Webster comments on the failure to provide resources for communal housing projects and notes that patients were frequently “discharged prematurely with inadequate follow up and support” (Webster, 1987). He further comments (1987) that “[g]overnment provision for [mental patients’] housing and accommodation is virtually zero. They frequently end up as rootless wanderers.” The lack of adequate funding was noted in the Burdekin Report (1993, p. 137), the national follow-up to the Richmond Report (1983), and the unforeseen costs of the deinstitutionalisation process have been noted (Wright, 1999; Smark, 2008). Such a view was echoed in comments by Webster in a 1987 interview, where social support systems such as inpatient facilities, outpatient treatment services, crisis teams, mobile teams, community mental health clinic staff, continuity of care, discharge planning, integration of hospital and community services, case management and psychosocial rehabilitation were found to be “abysmally inadequate” (Burdekin, 1993, p. 298; Cf. Singh, 2007).

The result of this policy failure is often social isolation (Nilsson and Lögdberg, 2008), homelessness for people who cannot sustain a fixed abode, or “trans-institutionalisation” (Brown, 1985b; Kirk and Therrien, 1975; Bostock and Gleeson, 2004; Topor et al., 2015), where they may end up in jails, hospitals, hostels, crisis accommodation or other institutions (Battams, and Baum, 2010), and where they cannot sustain necessary, regular medication (Holmes et al, 2005). Social rejection and a loss of self-esteem can result (Wright et al., 2000). Often great stress is placed on families who find themselves with a mentally ill family member who requires specialist skills that the families may not

possess. Very often, a gendered division of labour emerges, where mothers, sisters and daughters take on greater share of caring duties (Parks, 2003; Glenn, 2010; Levitsky, 2014). In any case, it seems that there is a continued dominance of “medical, charity and managerialist discourses around people with disability rather than those of rights and inclusion” (Chenoweth, 2000). Such dominance would certainly have a significant effect on someone who was homeless or semi-housed whilst experiencing schizophrenia. There is also evidence that, despite desinstitutionalisation, people with schizophrenia still feel deeply identified by and enmeshed in their illness; in Laing’s terms, their identity is still subject to ontological insecurity. Hannan (1990) argues that the chronically mentally ill do not feel a sense of “ordinariness” in their deepest level of self-identification and, in fact, identify with the illness, echoing earlier comments from Goffman about stigma. Despite these failures, however, there is still strong evidence that many patients in community centres have developed new senses of role and identity, independence, coping ability and capacity for forward planning (Newton, 2000; 2001).

What is the significance of the deinstitutionalisation process, both successful and unsuccessful, for the issues in the thesis at hand? Perhaps shorter stay in psychiatric hospitals has prevented people diagnosed with schizophrenia from forming an embedded “mental patient” or “sick role” identity (Newtown, 2001). Access to community activities and care may help the mentally ill feel less isolated and more secure in their identity. Alternatively, perhaps the lack of community or familial care has caused diagnosed people to feel lost or helpless. As we show in Chapters 6, 7 and 8, many of the interviewees led isolated lives. It is the task of this thesis to incorporate the understanding of the psychopharmaceutical complex and deinstitutionalisation with an analysis of both identity processes and power. Together, this analysis should throw light on the sociological processes involved in, and surrounding, the disruption, rebuilding and maintenance of identity in people diagnosed with schizophrenia. Indeed, the use of sociological theory throughout this thesis attests to the need to

move beyond simply biochemical accounts of schizophrenia and examine the social context of the illness.

CHAPTER 6

Results: Schizophrenia and Identity Disruption

The content of the twelve interviews undertaken for this thesis varied widely. Some spoke of optimism and hope for the future; others spoke of lost dreams; of crippling loneliness and ongoing symptoms. How to make sense of this material? Perhaps the most important step taken in this direction has been to divide the analysed results of the interviews into three Chapters – one dealing with identity disruption in schizophrenia, diagnosis, hospitalisation and relapse; one dealing with the various factors or behaviours that aided or abetted rebuilding a sense of identity; and one dealing with identity maintenance. Even within this structure, however, significant diversity of responses emerged. The data presented in these chapters tries to do justice to this diversity. However, at the same time, the researcher has tried to emphasise common themes, and to focus on issues relevant to identity disruption, rebuilding and maintenance; as well as issues of schizophrenia, identity and power.

This chapter presents material relevant to schizophrenia and identity disruption. It begins with an account of the disruption caused by the illness itself; by the sheer intensity and variety of symptoms of schizophrenia. Social isolation is a common emergent theme, as is misunderstanding of the condition by friends or relatives. It is found that in many, perhaps most cases, the experience of schizophrenia is so disruptive that it could take on the quality of an existential or ontological crisis. Similarly the shared experience of diagnosis often carried a significant challenge to the self-concept or identity of the sufferer caught up within the psychiatric apparatus. Hospitalisation emerged too as disruptive, but also, in some cases, as the location of stabilisation and even as a form of refuge.

Finally, relapse occurred in some cases as a reminder of the severity and significance of the illness; often a prompt to keep on taking medication.

Introducing the Respondents

Twelve people diagnosed with schizophrenia were interviewed for this study. Their ages and location varied, as did their symptoms – in both type and severity. This section gives an introduction to the respondents.

Prescott was a well-spoken 37 yr-old who was diagnosed with schizophrenia in 1999 and lived with his family in a small town outside of Canberra. Peter was a 47-yr-old unemployed man who lived in rural NSW and who was diagnosed with schizophrenia in 1988. Greg was a slow-spoken man of 44 years who was diagnosed in 2002, lived in western Sydney and who related feelings of paranoia and, in particular, persecution by neighbours. James was a seemingly happy individual of 46 years who was diagnosed with schizophrenia in 1988, and spent significant time with members of a church. Nathan was a 46-year-old unemployed man living with his mother as primary carer in western Sydney and diagnosed with schizophrenia in 2002. Ralph was a loquacious man of 47 years who was diagnosed with schizophrenia in 1991, lived in the south of NSW and who appeared to have come to an acceptance of his illness and life position. Michael was a well-dressed 34-yr-old man living in Sydney's inner-west who was diagnosed with schizophrenia in 2002. Danielle was a forty year old woman employed in the mental health field and living in the inner city who was diagnosed in 1992. Arthur was a solitary man of 62 years who lived a lonely life in Sydney's inner west with his companion, a small dog, and was diagnosed with schizophrenia in 1971. Caitlin was a woman diagnosed with schizophrenia in 2001 living alone in Sydney's south-west. Gale was an unemployed woman of 49 years who was diagnosed with schizophrenia in 1991 and lived in Sydney's south-west. Finally, Sally was a woman of 61 years who was diagnosed in 1994 and lived in western Sydney.

The Impact of Schizophrenia

Chapter 4 of this thesis has suggested that people with schizophrenia generally experience some kind of instability or breakdown in their sense of identity. This may constitute a phenomenological breakdown. This suggestion is borne out to some extent. However, a number of different themes relating to identity and schizophrenia also emerge.

We begin with circumstances where the research subject's identity or personality was changed by their illness. As Bury suggests, schizophrenia is a chronic illness and, as such, often brings "biographical disruption". Prescott, who was diagnosed with schizophrenia some 13 years before the time of interview, makes the observation that his personality changed both with, and after schizophrenia:

Prescott: I think that's, that's interesting that the illness has affected my personality, I think it's true. It has, so I am a new person. I was a person until I was in my late adolescence and then I was a different person during psychosis and I've come out the other end, a combination of the two.

This can clearly be seen as a form of biographical disruption. Indeed, Prescott describes a complete change in his identity or personhood. The illness has rebuilt his personality. This echoes themes of ontological insecurity described in the Theory Chapters, as well as descriptions of schizophrenia as an "I am" illness, rather than an "I have" illness. Interestingly, such a change occurred as a *process*, as predicted by symbolic interactionism. With that said, symbolic interactionism has some trouble accounting for specific symptoms that people such as Prescott experienced (described below), other than as a compromised interaction. More will be said of this issue in Chapter 9. Another significant point to make is that this change seemed to come as a result of the illness itself, not by the social situation that Prescott found himself in. Prescott links his "biographical disruption" to delusions and convictions:

Prescott: It took years, it took years, to get me to have to have understanding and acceptance of my condition.

RS: Why did it take you so long?

Prescott: Because of the nature of the condition. Because, um... um um because it was hard to have insight at the very beginning because of my convictions and my delusions, my convictions and my delusions were so prominent in my perspective of life.

Although symbolic interactionism may have some difficulty in making sense of such convictions and delusions, we may turn to phenomenology for a better description. In particular, we find that Prescott's symptoms suggest Binswanger's "breakdown in the consistency of natural experience", or a breakdown of the body-in-the-world from Merleau-Ponty's point of view. Unlike many people afflicted with schizophrenia, Prescott also has the insight to see that his illness has caused him to lose life opportunities, in a sense shrinking the possibilities of identity development, but also opening opportunities for successful medication and treatment. Insight has a particular psychiatric definition: it involves "the patient's awareness of mental disorder, awareness of the social consequences of disorder, awareness of the need for treatment, awareness of symptoms and attribution of symptoms to disorder" (Mintz et al, 2003, p. 75) and is often seen by psychiatrists as a significant step in overcoming psychosis. Prescott further talks of lost opportunities due to his illness:

Prescott: I definitely have missed out on life's opportunities.

RS: Can you tell me a bit about that.

Prescott: Yeah OK, um, I mean getting ill the first time and having time off uni, getting ill the second time and lost a girlfriend, um, we broke up. Being responsible, earning money, doing normal things, like getting married and having a family, having a mortgage, you know, having a social circle of friends, you just lose all that. Not to have that is a big part of your life. That's certainly something that I've lost.

These lost opportunities would certainly interfere with his ability to develop a more viable self through the process of social interaction with others, particularly inhibiting his ability to internalise the views of the general other. As we will see in the next Chapter, such a process of view internalisation, predicted by symbolic interactionism, will prove a vital element of rebuilding a sense of identity.

Peter, who was diagnosed with schizophrenia 24 years before the time of interview, emphasises that schizophrenia changed his personality by making him paranoid, so much so that he would close all the doors to his house to prevent neighbours from listening to him:

Peter: Um, well you tend to have um, quite a paranoid personality when you got schizophrenia, but the illness has, say from when I was young, it's changed my personality to the extent that I'm exceptionally careful and um whatever um, for instance, ah you know I made sure I closed the door so that the neighbours couldn't hear and this sort of thing. You tend to ... ah ... be a bit paranoid but at the same time ah you're aware of what's happening around you.

As an illustration of Peter's ongoing symptoms, Peter closed his house doors during the interview to prevent neighbours from "listening in". As Peter points out, this paranoia has changed his personality, and perhaps echoes Minkowski's "loss of vital contact with reality". It also suggests the concept of biographical disruption; indeed, the disruption may be so severe as to pass beyond the purview of the concept of biographical disruption. Perhaps we require a more developed conceptualisation of disruption in people diagnosed with schizophrenia. We must also again be aware that the paranoia Peter felt and feels probably comes as a product of his disease, not his social context. There was in all probability no real conspiracy of neighbours listening in. This is also a paranoia that Peter has carried with him since first developing schizophrenia, through diagnosis and treatment. Amongst the respondents Peter was far from alone in continuing to experience identity-threatening symptoms through diagnosis and treatment. Again, symbolic interactionism may prove somewhat limited in accounting for a dysfunctional self as expressed through paranoia, and we may have to develop a concept of "compromised" gesture or interaction, as well as looking to the contribution of phenomenology, in describing symptoms such as these. This point becomes more salient in Chapter 9.

Peter described the impact of the illness as a belief that people would "pop him off".

Peter: Yeah, yeah, I was on the north coast of New South Wales and uh, I thought that um, the drug dealers were trying to pop me off and ah, and ah, I thought that ah if I went to sleep they were going to pop me off in my sleep,

cause I seem to get the impression that that's how they do it, they wait till you sleep and then pop you off and so I seem to remember ah, being chased from town to town in my car and people were saying things like ah, "wait till he's asleep and then pop him off" and all this sort of thing.

Greg, who was diagnosed with schizophrenia 10 years before the time of interview, related similar feelings of paranoia and persecution by a neighbour. Again, symbolic interactionism may prove of limited use in accounting precisely for such symptoms:

Greg: I was diagnosed in 2002, um, ...pause..., ah, it came with a psychotic episode where I thought I was being pursued by ah people associated with my parents' neighbours, um... when I first um, I had this neighbour who used to yell out a lot of stuff, shout out, and I started shouting back because I thought it was unfair that he was doing that.

James, who was diagnosed with schizophrenia 24 years before the time of interview, talks about relating to people through "indirect information", believing he had dreams from other people's point of view. Such experience clearly suggests a breakdown in Merleau-Ponty's picture of the individual as body-in-the-world and, perhaps, an experience more intense than mere biographical disruption. This form of pathology is also interesting in that it confirms the symbolic interactionist thesis that a competent self develops out of relations with, and from the viewpoint, of the other. James cannot adopt the general view of the other due to his condition. What is perhaps more interesting is that this process of self-formation from the point of view of the other appears to be occurring in an entirely transparent and conscious way:

James: [T]here's times where I would relate to people not on the basis of how they were relating to me but on the basis of information that was wrong that I thought was real because of the schizophrenia. So I, like I had instances where I had dreams from other people's points of view before things happened and so then when I was in the situation I thought I knew what their point of view was, because of the dream but um, actually I didn't, so I wasn't necessarily relating to people based on how they were relating to me, I was relating on indirect information.

Later in the same interview James reiterates that schizophrenia made him a "different person", confirming themes in the literature review that schizophrenia can have severe consequences for the ill person's identity. We may make the point here that it is the schizophrenia that is making James a

“different person”, not directly a process of symbolic interactionism. This observation confirms the point made earlier and in Chapter 3 that symbolic interactionism often fails to account for dysfunctional or deviant selves. Again, short of renovating symbolic interactionism (as we attempt to do in Chapter 9) we may turn to phenomenology to account for the dysfunctional self. James’ voices present a breakdown of the body-in-the-world, where his awareness or perception of the world was in question.

James: ...the schizophrenia made me a different person because I was not always responding to my environment appropriately because of voices in my head or information that I had that wasn't real, thinking I could read someone's mind or something but also um once the diagnosis of schizophrenia came um it made me aware that not everything that I had I got through my head, through my mind was accurate and so yeah, I was a different person, cause I was a person who could no longer completely trust everything in their own mind.

This experience of schizophrenia prevents James from working and living a productive life. He is suffering a phenomenological and existential threat that may move beyond mere biographical disruption. He identifies the fact of not being able to contribute to society or look after himself; prime measures of identity in the larger community. James’s comment about death draws on a darker theme in the literature on schizophrenia, namely that a significant number of people with schizophrenia attempt suicide. Such action would represent the ultimate antithesis of rebuilding a sense of identity – final identity negation:

James: Um, [pause] it just means that I'm unable to be productive in the way that society values, I can't, I don't have a family, I can't look after myself properly, I'm not contributing to society in the way that a lot of people would see somebody contributing to society. Um and um [pause] sometimes it's like, it would just be so easy to just to die.

This quote also draws attention to the deep desire of people with schizophrenia to be “productive”, an understandable desire in a society where the work ethic predominates and employment is seen as a key correlate of successful identity production.

Nathan, who was diagnosed with schizophrenia 10 years before the time of interview, speaks of his symptoms as the emergence of an inner child, a process that threatened his sense of what had and hadn't happened in his life:

Nathan: the schizophrenia I have and I'm not sure if this is the same that's determined in the literature but it consists of at various stages um almost like my inner child comes out um wanting answers for things that have happened in the past, some of which actually didn't happen at all.

The concept of an inner child "wanting answers" was a singular one amongst persons interviewed.

This distinct experience of identity disruption helps make clear the variety and individual nature of symptoms experienced by different people with schizophrenia. Perhaps we can make a comparison here with Lysaker and Lysaker's (2008) concept of a cacophonous self, where multiple identities seem to emerge from the single person. On the other hand, we may be able to compare Nathan's experience of schizophrenia as a sense of vertigo to Laing's concepts of "engulfment", "implosion" and "petrification" or "depersonalisation". Interestingly, the idea that his inner child was "wanting answers for things that may have happened in the past" may suggest a psychodynamic element to the illness, a return-to-childhood that is possibly amenable to psychoanalytic treatment. The phenomenological dimension of his emotional experiences also emerges as significant, affirming our use of phenomenological theory. Nathan's fluctuating panic, anxiety and anger are both emotional responses that are not strongly thematised in a symbolic interactionist position that emphasizes cognitive processes:

Nathan: It's like vertigo, I get this vertigo feeling where I start to think "Oh no, I'm gonna fall over, I'm gonna collapse, I'm gonna hit the ground" um I get panic attacks, I get anxiety, I get periods of, you know, anger, just absolute intense anger that I feel towards society, that I feel towards those doctors and then I think, "oh maybe I was delusional" and then later on I think, "yeah I was delusional" and what scares me is about my own internal anger level, how that goes from 0 to 100 in a millisecond

Another emergent theme in the data is that of deteriorating thinking caused by the illness, perhaps echoing Minkowski's phenomenological concept of "poor autism" or Sass's account of negative symptoms. The concept of deteriorating thinking also confirms the symbolic interactionist insight

that thought is generally a product of successful, meaningful interaction. Insofar as this is true, we may qualify the argument that symbolic interactionism fails to account for dysfunctional selves.

Ralph, who was diagnosed with schizophrenia 21 years before the time of interview, had a sense of acceptance of his situation that emerged in a lengthy series of narratives he unfolded in response to research questions, confirming the importance of narrative for many people diagnosed with schizophrenia. Such descriptions, or “narratives” play a vital role for many interviewees, providing a way of making sense of, and “owning” their illness, and healing the temporal breach of psychosis. For example, Ralph described the descent into schizophrenia through speaking about job opportunities and troubles taking care of himself.

Ralph: And I studied in Adelaide for 2 years, studied politics and philosophy, um and at the end of the 2 years um I wasn't able to um submit my exams, sit my exams or submit the required course work because my thinking was deteriorating and um when I was around um, I was living with 2 guys I went to infant school with who happened to be in Adelaide and um they were a bit concerned for my welfare and around the same time, I left university um and they found me a job in a petrol station where I was in a petrol station for about um 12 months working and unfortunately, again it was quite socially isolating in that I worked the night shift and um had trouble taking care of myself.

As we have seen in Chapter 4, there are a number of descriptions of the nature of psychosis, and people experience psychosis differently; some may be delusional, others experience hallucinations, distorted or confused thinking or present with negative symptoms, and so forth. Furthermore, the content of delusion, hallucination or confused thought may change from person to person. The fact that such different perspectives may emerge and all be labelled as “schizophrenic” suggests that we must be careful with our use of the term, and recognise that the various schizoid illnesses described in the DSM cover a variety of pathological mental states. In the current case of Ralph, these perspectives point to ontological insecurity; fragmented, divided and lost selves; psychosis as an “I am” illness – an illness where the patient “is” schizophrenic, not merely where he or she “has” schizophrenia. Again, it seems we must move beyond the mere description of biographical

disruption to something more serious, more intense. Ralph describes the psychotic experience as “entering a new country”. Such experience again testifies to the individual and distinct nature of schizophrenia symptoms:

Ralph: when I get unwell, I forget that I’ve ever been well and all of a sudden I’m in that country of psychosis that’s always been there, and I forget all those strategies that I’ve used to overcome my illness.

This psychosis created circumstances where everyday activities relating to identity may become difficult or impossible – the meaningful interaction with particular others is inhibited; the sufferer cannot absorb the view of the general other; a good case for the moniker “biographical disruption”:

Ralph: I found it so incomprehensible I didn’t know what was wrong with me and it’s kind of like trying to run when you’ve got a broken leg, not knowing you’ve got a broken leg and just continuing to fall over.

Finally, we have a number of distinct responses to having schizophrenia. Interestingly, Michael, who was diagnosed with schizophrenia 10 years before the time of interview, spoke of personal development coming as a result of having the illness.

RS: Did being ill, change your personality?
Michael: Um, no, I just grew up a lot quicker, that’s all.

Perhaps Michael was denying the real impact the illness had upon him? Indeed, during his interview, he remained shy about questions relating to his illness and preferred discussion of his love of fashion and how he was out-fitting his apartment. On the other hand, perhaps he did not have as intense an experience of schizophrenia as other respondents. The answer to such questions is not always forthcoming during such interviews. Michael’s short response indicates, perhaps contrary to the thrust of this thesis, that the self may in fact *develop* or *progress* as a result of illness. Such a possibility, perhaps supported by the case of Ralph (below), would suggest that we could regard schizophrenia as an opportunity; a possible time or space for personal development. Such development would seem to rely upon the situation and personality of the sufferer, not to mention the intensity of residual symptoms. An outcome of this kind would be worthy of further analysis.

Danielle, who was diagnosed with schizophrenia 20 years before the time of interview, describes the strangeness and intensity of pro-dromal and onset of schizophrenia through a desire to “chuck everything out” and conflict with her father. It seems as if the pro-dromal phase of schizophrenia has itself emerged as a desire to disrupt her own life. This finding points to the importance, not only of diagnosis, but of pro-dromal experience as a disruptor of biography and the processes of regular symbolic interactionism. Danielle’s experience also clearly included agitation, anger and aggression, three emotions marked by Ball et al. (2005) as emergent factors in their “theory of crisis for individuals with severe persistent mental illness”.

Danielle: then one day I just chucked out everything that I had, all those important documents and books and everything, and I chucked them all out and that was when my parents divorced at the same time as well and from then on it all just went downhill and I didn't really care anymore what happened.

RS: Why did you throw your stuff out?

Danielle: I don't know, I felt, I think that was the beginning of my illness or something, because I felt like, I can't remember exactly why, but I remember I was about to throw them out but I thought I'll keep them if Dad doesn't say anything and then I threatened to Dad that I was going to throw all these things out and he said "Oh, I don't care, go and throw them" and then I just did and I threw them out.

Rejection by one’s parents, as evidenced here, would no doubt have severe personal ramifications. It may reinforce the social isolation felt by many people diagnosed with schizophrenia, as well as having a negative impact upon rebuilding identity.

The Impact of Diagnosis

It was expected by the researcher that the diagnosis would typically serve as a node, or turning point, in the research subjects’ experiences of schizophrenia. In many circumstances this was true, supporting Charmaz’s observation (1983) that the doctor/patient relationships could be a significant sign of prognosis and could lead to heightened self-concern allowing the patient to analyse relationships with other people for discreditation and negative self-reflections, as well as greater

dependence on others and a need for social contact. As we have seen, Hayne also points out the importance of accepting the diagnosis for individual development:

[A]s the pain, grief and loss fluctuate in intensity from day to day perhaps, the “prediagnosis self” becomes less and less recognizable. The individual must struggle to rebalance, to take stock of altered functions, to regroup. This is the only way to move forward and to move forward includes the challenges of finding a level of wellness within the illness and within the knowledge of the illness brought by diagnosis (2001, p. 17).

A similar argument is made by Kelly and Field (1996). It would seem that diagnosis was generally experienced as a negative, perilous experience by the participants interviewed. In any case, the symbolic interactionist perspective adopted by this thesis suggests that the impact of the diagnosis of schizophrenia must be understood as the outcome of a very particular set of meaningful interactions between psychiatrist and patient. We must also acknowledge at this point the analysis of Michel Foucault, for whom the nexus of power/knowledge concentrated in the psychiatric profession helps shape and, in fact, *produce* the individual diagnosed with schizophrenia as a willing recipient of medication and medical intervention and ready for release into the community. In Foucault’s analysis, diagnosis emerges as a vital point of contact, or fulcrum, around which the power of the psychiatric profession turns. Indeed, the relationship of power and influence exercised by psychiatrists over patients was implicitly accepted by almost all people diagnosed. We may perhaps further engage with Foucault’s analysis to see the power exercised by psychiatrists through diagnosis as a form of “confession”, in which the sufferer unburdens him or herself of his or her symptoms to the all-knowing psychiatrist. This analysis resonates, to some extent, with interviewee accounts of diagnosis.

On the other hand, the diagnosis of a psychiatric illness with clear label and treatment options was not received by all as a threat, but for some came as a relief. In either case, the diagnosis could be seen as an important point upon the patient’s “illness trajectory”. Likewise, time in a clinic or hospital, considered below, could come as a relief – as an “asylum” in the true sense of the word.

Arthur, who was diagnosed with schizophrenia 41 years before the time of interview, describes a strange experience of diagnosis, one where he only found out the specific diagnosis some time after seeing a psychiatrist. This was not a common experience although, as we will see, some interviewees were only diagnosed after a lengthy period of time. Despite such time, Arthur still trusted the opinion of, and submitted to the analysis of, the psychiatrist, confirming Foucault's analysis of the power of the psychiatric profession.

RS: Were you diagnosed by a GP or a psychiatrist?

Arthur: I think he was probably a psychiatrist but I didn't really get to find out what his precise qualifications were, I mean, you know I saw a bloke who was in, you know, in charge of whether or not I got pensioned off or not, you know and later got his paperwork, I think he was probably a psychiatrist, I think. I'm not sure, you know. Anyway, he's the one who wrote on the letter, wrote on the form that that was his diagnosis, schizophrenia, anyway.

Arthur describes the impact diagnosis had on his life; an impact one could fairly describe as a biographical disruption:

Arthur: Well I didn't have a psychiatrist at that time, I was working for the public service and obviously they saw my hope of doing any work was almost nothing, so they sent me to the Commonwealth Medical Officer and he told them that he didn't think that I would ever be able to hold down any kind of job, as long as I lived.

RS: How did that make you feel?

Arthur: Ah well, I had already pretty much accepted that was probably going to be the reality for me because I was only 20 years old at the time and naturally to suddenly be felled with such staggering unusual and crippling problems, you know, I didn't think I would just get up this morning and be like everyone else again.

Arthur also commented on the brevity of his visit for diagnosis. Such brevity could cause angst or upset in the diagnosed patient; especially when such a significant diagnosis was being pronounced.

Perhaps it is the implicit trust people have in doctors and the psychiatric apparatus that allowed

Arthur to pass through this experience without excessive anger:

Arthur: He was fairly brief, you know, but I think, I guess you know he, I guess he could see they symptoms I was talking about were pretty rare, you know and I don't suppose it took him long to come to his conclusion I suppose.

As noted above, some people were only diagnosed after a significant period of time. Prescott describes the situation where it took a psychiatrist three years to diagnose him. In this case, the psychiatric apparatus again seems to have failed in its central mission of the identification of mental illness accurately and promptly. Nevertheless, he harbours no ill-will about the time taken before diagnosis and does not blame the psychiatric profession:

- Prescott: I originally saw a psychiatrist. I was admitted to hospital being extremely underweight. This was in 1995 and today is 2013, so it took a few years after that that I got a diagnosis. So in the first place, um I was admitted to hospital and eventually assessed by a psychiatrist to have suffered a psychiatric ... sorry, a psychotic episode.*
- RS: How long did that take?*
- Prescott: The...?*
- RS: How long did it take for the doctor to diagnose you?*
- Prescott: About three years.*
- RS: Three years. Why do you think it took so long?*
- Prescott: Because they're cautious about giving a diagnosis like that without having enough substance or experience or exposure to the condition that they won't give a diagnosis for at least three years.*

Prescott speaks in fairly positive terms about the diagnosis, one he accepted and trusted without full understanding. He clearly accepted the functioning of the psychiatric apparatus. This points again to the implicit trust most citizens have in doctors and the medical profession, especially where an illness as severe as schizophrenia is diagnosed. The fact that the psychiatrists were friendly serves to reinforce their influence:

- RS: OK, and what did it feel like being diagnosed?*
- Prescott: They sort of sat me down and said "look Paul, we believe that you've got this condition that's called schizophrenia" and I thought; that was the question, wasn't it, what I thought about it?*
- RS: Hmm.*
- Prescott: Um, I thought it made sense, because everything that I experienced was similar to what they were explaining to me what it was going to be like.*
- RS: OK, so they gave you an accurate picture of what schizophrenia was like?*
- Prescott: Not an accurate picture, they never explained to me what it was that it um, what they were looking for in me, but they explained to me that I had this condition. As far as I could understand it was I thought it was.*
- RS: Did you trust what they were saying?*
- Prescott: Yes.*
- RS: Were they friendly towards you?*
- Prescott: Yes.*

James describes a circumstance where, like Prescott, it took the acting psychiatrist some time to diagnose, but again he implicitly trusted the psychiatrist. As we see, James also built up a trusting relationship with his psychiatrist; an important form of symbolic interaction with a specific other :

James: So I found a psychiatrist, my mum actually rang up a church, a Wesley Central Mission and asked them if they knew any Christian psychiatrists, and they recommended one and I went to see him and he was really good so I started seeing him in the beginning of 1994 but it wasn't until about 1998 that he actually diagnosed me with schizophrenia but that was good because, like it meant that by the time it happened, he had built up the relationship to the point that I felt like I could trust him enough to accept the diagnosis.

Caitlin, who was diagnosed with schizophrenia 11 years before the time of interview, describes ambivalence about adopting her diagnosis, an understandable reaction given that schizophrenia is such a heavily stigmatised illness and can present such a serious break in the sufferer's ontology.

Perhaps Caitlin was experiencing negative feelings about being "labelled" as a "schizophrenic". Note also how Caitlin associates accepting the diagnosis with taking the correct medication, perhaps implying a link between the psychiatric apparatus that diagnoses and the psychopharmaceutical complex that medicates. This link will be explored further below:

Caitlin: I was hearing voices, yeah, yeah, that was the main thing. And I'd get messages from the TV and the radio and I'd get very depressed and I'd isolate myself and yeah but um, I had severe depression and I went to a psychiatrist here about 12 year ago and he said "well you've got schizophrenia" after talking to him.

RS: And how did you feel about that?

Caitlin: Oh well, it took a while to accept but now everything is you know, I accept it and I am taking the right medication and that.

Caitlin has clearly come to the point of accepting her condition and the disruption it entails. She repeats her story of accepting the diagnosis, responding to the idea that she was "labelled":

RS: How did it feel like getting diagnosed?

Caitlin: Um I was a bit shocked, yeah.

RS: Did you feel like you were being labelled?

Caitlin: Yeah, sort of yeah. You know um but now you know, I just accept it, you know, it's just one of those things.

Subsequently Caitlin offers a non-committal response about her identity as a person with schizophrenia, again pointing to the stigma of the condition, although she still experienced hearing negative voices that would form a breakdown of the regular body-in-the-world, and met with a carer regularly. We may also understand Caitlin's non-committal response as a form of resistance against the psychiatric apparatus and a society that stigmatises schizophrenia. Such resistance, though theorised to some extent in the work of Foucault, will prove, in Chapter 9, a significant feature in the theoretical attempt to move beyond Foucault in describing contemporary relations of power in the mental health system:

RS: So, do you see yourself as a schizophrenic?
Caitlin: (pause) I don't know, that's a hard question. You know (pause) yeah. A very hard question. You don't like to be labelled do you. No. (pause) I don't think I can answer that one.

Peter also did not trust the diagnosis for a significant period of time. Such a response is not entirely unique. Many people outside the study suffering schizophrenia seem to do so without full insight into their condition, often disbelieving psychiatrists or family members trying to convince them they "have a problem":

RS: OK and what was that like being diagnosed?
Peter: Um, well I didn't believe that there was anything wrong with me, I thought that the medication was making me psychotic.
RS: And how long did you believe that?
Peter: For years, yeah.
RS: But you still took the medication?
Peter: Um, for a while, I took the antidepressants for quite a while and then I took the Stelazine for six months and then I decided to go off it all and that's 10 years after that I had the extreme psychosis.

Danielle had a generally positive experience with her diagnostician...

RS: Were you diagnosed by a GP or a psychiatrist?
Danielle: By a psychiatrist.
RS: How did he behave towards you?
Danielle: She was quite gentle and sort of, I don't know, she just was a doctor.

...but like Peter resisted her diagnosis. (Note, as an aside, the researcher's gendered assumption that the psychiatrist was male). Resistance to diagnosis must be understood as a fundamental experience in our study of schizophrenia and identity. It seems that even when resistance is strong, changes to a person's personality (or identity) can be intense enough to encourage loved ones to seek out medical help for the patient. The Foucauldian theme of resistance as an integral part of the psychiatric relationship is developed in Chapter 9, and will in fact help us move beyond Foucault's conception of the disciplinary institution:

- RS: Did you know something was wrong?*
Danielle: No, I didn't want to know, I didn't know something was wrong and when I got diagnosed later on I kind of didn't want to be diagnosed with that label later on.
RS: Why is that?
Danielle: Oh, cause I don't know, cause I was brought up just believing that I'm normal and you know that I can do things

She made clear what was unwanted about her diagnosis:

- RS: What did you not like about being diagnosed?*
Danielle: I just like, cause I always thought I was normal and I never thought I had anything wrong with me.

Ralph had a somewhat different response. He was relieved to make sense of an incomprehensible experience. Here we must differentiate between the initial pathological response, often hostile, where diagnosis confirms a great personal disruption and points towards further breakdown, and the accepting response that seems to be the first step on the path towards self-acceptance and rebuilding a sense of identity explored in the next chapter. Interestingly, it was Ralph's social location that forced upon him the realisation of his illness; a kind of acceptance of the view of the other as posited in symbolic interactionism:

- Ralph: it was um [pause] about a week after being in hospital I kind of clicked to the idea that I was in a psychiatric ward and I kind of thought "you know, if I'm in a psychiatric ward there must be something psychiatrically wrong with me and if that's the case, what am I to do'?"*
RS: How did that make you feel, knowing that there was something wrong with you?
Ralph: Relieved.

As noted, Ralph's experience was also one where he turned the diagnosis into a positive life outcome. Like our discussion of Michael, it seems that identity disruption of diagnosis may not always be an entirely negative experience, as emphasised in the Theory Chapter:

Ralph: I think my diagnosis caused me to become a lot more reflective um, um it caused me to become a bit more, I wouldn't say intuitive, but you know, listen, listen to my conscience a bit more um, it certainly caused me to be a lot more compassionate towards others.

Ralph also had an experience where he felt close enough to his psychiatrist not only to trust his diagnosis, but to discuss possibly living without psychiatric medication. Again, we must emphasise the importance of a healthy state of symbolic interaction between two or more valid actors as a precursor to illness management, rebuilding a sense of identity and wellness. Ralph's case also complicates a one-dimensional, or top-down, picture of the psychiatric apparatus; in the present case, a form of negotiation occurred between the patient and psychiatrist, not entirely a dictation of diagnosis and medication by the stronger power. Perhaps such negotiation may be easier in a context where there exist a number of psychopharmaceutical interventions from which a treating doctor may choose, or where the opportunity of psycho-social interventions may be present. The presence of the element of negotiation may perhaps also temper historical criticisms of clinics, hospitals and asylums. In any case, there would seem to be a correlation here between the equanimity with which Ralph accepted his diagnosis and his openness to discussing medication. As we show in later chapters, Ralph's cooperation in determining his medication can be read as a form of illness management conducive to rebuilding a sense of identity:

Ralph: I even had a conversation with my psychiatrist about whether being, living without medication in a psychotic state would be beneficial and I said to him "the thing that tires me out the most is that psychotic thinking", because I think I can solve it, whatever it is, I don't know, that, you know the world is an inherently messy place and you know when I'm psychotic and unwell I think I can make some understanding or some order of that world.

A similar sense of relief upon diagnosis was felt by Michael:

RS: *OK, um, how does it feel, you said it felt good to be diagnosed ... why?*
Michael: *Cause it was a lot off my mind, my mind was released.*

Greg attested to the changes brought on by diagnosis:

RS: *Was the How did you feel about your diagnosis?*
Greg: *I don't know, um, I just wanted it to stop. Yeah?*

In particular, the strength of his symptoms, equivalent to a disruption of the body-in-the-world, caused him identity upset. It is difficult to begin the rebuilding a sense of identity process suggested by symbolic interactionism when one feels too persecuted to interact at all:

Greg: *Probably thought it would make sense but the symptoms were so real, yeah. I thought even though I had constant screaming in my head, I felt persecuted in real life as well. Yeah.*
RS: *And did this make you a different person?*
Greg: *Yes it did.*

And later...

RS: *And how has it changed your life?*
Greg: *Well, um, I lack motivation, um ...pause..., I'm not working at the moment, ah, and I've worked on and off ever since, different jobs, um, ...pause..., it's just been a real negative in my life.*

The emphasis on work here is interesting. The importance of employment for identity formation emerges, particularly in a society where the work ethic is closely related to recognised forms of identity. Greg also again picks up on the theme of motivation and being a "real negative". His story is incredibly sad and is a testament to the power of external stigma to be internalised by the sufferer of schizophrenia:

Greg: *I just don't think I'm worth much and, um, I lack a lot of confidence now, yeah, it's like I've been cut down to size. Yeah.*

Finally there is the issue of dual diagnosis, or mental health diagnosis with a substance abuse condition. Such problems would seem to complicate the analyses pursued in this thesis. That is to say, the expression, behaviour and thoughts of someone with both a substance abuse problem and a diagnosis of schizophrenia may be hard to "pin down", so to speak. It may be unclear whether a

disruption of one's identity has arisen as the result of the substance abuse problem, or the psychiatric diagnosis.

Nathan commented on his own substance abuse problems, which seemed to have intensified the impact of the illness.

Nathan: I had developed a substance abuse disorder alongside the schizophrenia but I found that having the substance abuse disorder made the schizophrenia worse; the symptoms of the schizophrenia for me.

Indeed, Nathan paints a picture of himself as a drug addict, "hidden away from society". Again, symbolic interactionism suggests that shying away from social contact may reinforce identity disruption and negatively affect processes of identity-reformation. Another significant point to be made here is the importance in Nathan's account of the sense of shame he felt at being a drug user. Such shame may represent an internalisation of the external stigma of drug use or mental illness. Importantly, however, it also highlights the significance of the emotional state of the actor engaging in social interaction – a theme not strongly dealt with in symbolic interactionism. As we will see in Chapter 9, symbolic interactionism may perhaps be renovated to take account of such states.

Nathan: the situation that I was doing it meant that I would have to keep my door shut, I had to close myself in my room, smoke my bong and be hidden away from society ashamed of myself, yet addicted.

But like other respondents, Nathan did not respond well to the fact of his need for medication. The rejection, or negative feeling about being medicated may arise from a desire not to be "labelled", a distrust of the medical/psychiatric establishment, or even a belief, delusional or otherwise, that one is not "sick". One may understand such beliefs as a form of resistance to the psychiatric apparatus; a resistance we must take account of in our picture of the power of hospitals, clinics and the psychiatric apparatus. In the case of Nathan, the resistance to medication rose out of a desire to experience life "naturally", without the lens or perspective of a mind-altering substance:

Nathan: I didn't like Cipramil, I didn't like Lexapro, I didn't like um, Effexor and Zoloft and all these different anti-depressants because they made me feel high and I didn't want to feel high, I wanted to feel just more or less enjoying life as natural as possible, um but when I was put on schizophrenia, it was like "you must take medication for the rest of your life'...

RS: It's OK.

Nathan: Um, "you must take medication for the rest of your life" and be under psychiatric care for the rest of your life.

Greg also suffered a dual diagnosis, being an alcoholic when diagnosed, and had smoked pot occasionally from age 16.

The Impact of Hospitalisation

Upon hospitalisation many respondents accepted that there was "something wrong" with them – typically a form of biographical disruption – and they were going to the "right place". The progress of schizophrenia-diagnosis-hospitalisation can be understood as a common "illness trajectory" and may confirm for many patients that there is something significantly wrong with them. Some patients came to accept, if not appreciate, the hospital as a place where they could find peace and could exist without major stress for a period of time. The hospital in this sense is clearly a fundamental, if sometimes brief, aspect of the illness trajectory of the person diagnosed with schizophrenia, as well as being for a time the key social structure that surrounds the diagnosed person. With that said, it is not surprising that respondents who had been scheduled or otherwise forced into hospitalisation generally reacted negatively to this experience. The issues surrounding power and forced hospitalisation are treated more extensively later in this thesis.

Prescott was originally hospitalised for a weight condition that gradually formed a psychotic episode. Such a career, or trajectory, is not exclusive amongst respondents. Typically, a patient may forget to take medication or, once medicated, "feel better" and decide the medicine was un-necessary. Such patterns of behaviour typically resulted in re-hospitalisation; having a psychotic episode seemed to

be the common denominator amongst people admitted to hospitals, clinics or psychiatric wards. Such a pattern emerges in the quote we saw from Prescott on page 116 regarding hospitalisation. Later in the interview Prescott continues with the observation that he was re-hospitalised after suffering relapse due to “going off” his medication. Such an experience is again common among people who were hospitalised multiple times. What is the relevance of this? It confirms the primacy of medical intervention, even whilst clinics or wards may play a shortened role in a deinstitutionalised environment. The shift towards deinstitutionalisation draws on critiques of the asylum or mental hospital such as those given by Goffman, as well as being premised by the belief that people with mental illness are best treated within the community. It is a sad reality, however, that many people with serious mental illness do not currently receive adequate community support and may live isolated, if not fragmented and peripheral, lives:

Prescott: I was in the hospital initially, for about two months and after that, I was returned home, medicated and it wasn't until another year or two down the track that I had the symptoms again after going off the medication.

Prescott's description here of returning home, medicated, exemplifies the point made above that the psychiatric apparatus has exercised a productive power over Prescott's self, whilst also shedding a more positive light on the deinstitutionalisation process. Prescott gives a positive account of co-patients of the hospital below.

The significance of meeting co-patients, some in better and some in worse condition, is an interesting side-issue. Does such a meeting encourage the patient to “do better”, or depress the patient about the condition they have? Symbolic interactionism would suggest that any social interaction with another should benefit the process of rebuilding a sense of identity. But how would such interaction best be provided? Would a person suffering intense paranoia or delusions be best treated within the confines of a clinic or psych ward, or perhaps in the open expanses of a farm or park, or through social workers and psychiatric carers at home?

Prescott uses the term “consumers” to describe fellow people “consuming” the mental health product. Such a term seemed to serve to create a distance between the diagnosis of schizophrenia and the way it was discussed:

- RS: Oh, you started in a psychiatric hospital ... So, and how were the other people there.*
- Prescott: The staff?*
- RS: Not the staff. The other patients.*
- Prescott: The other consumers?*
- RS: Yeah.*
- Prescott: Yeah, I didn't quite, ahhh, I thought they were just completely normal people. I mean they obviously had their issues and now thinking about it, the same time (pause) yeah, it's a bit of strange situation, all the consumers together like that, because there is obviously that locked area that they don't let you in and you got to stay inside the locked area they keep you in and you have to relate to people. So, you can't just run away.*

Prescott's comment here that he thought “they were just completely normal” is interesting; the mentally ill seemingly did not express the stigmatic symbols one would expect. Finally, Prescott also accounts for a sense of powerlessness in the hospital. Such an experience is not unique. Generally persons admitted to mental hospitals or psychiatric clinics had to give up certain freedoms. Their experience of dispossession was certainly not as stark as that described by Goffman in *Asylums*, or the disciplinary institution of Foucault in *Discipline and Punish*, but was nevertheless significant. Indeed, Prescott's comment about “answer[ing] questions from the doctors” brings to mind Foucault's analysis of the confessional as an exemplary social structure:

- RS: And did you feel that the hospital was exercising power over you?*
- Prescott: A little bit. Um, certainly because I had to take the medication, I had to, you know, answer questions from the doctors and that sort of thing. So, you do feel like they had a bit of power over me.*
- RS: Yeah. And did that make you feel powerless?*
- Prescott: Well, yeah, it did a little bit; when I first got in the hospitals.*

Hospitalisation seemed to help Ralph understand his psychiatric situation. He had achieved insight – indicated by the quote from his interview regarding his self-realisation whilst in a psychiatric ward on page 119 – a key to avoiding future hospitalisation, and a necessary condition of symbolic interaction. Such an achievement is treated by psychiatrist orthodoxy as a positive, if not

fundamental, step in recovery, and, it would seem, a step towards the process of rebuilding a sense of identity. Indeed, Ralph came to see the psychiatric wing of his hospital as a kind of refuge. Such a view certainly seems at odds with historical critiques of the asylum and the social control of people with mental illness. Nevertheless, it is an important sub-theme in the data, as it provides a more subtle and balanced view of issues of power and hospitalisation:

Ralph: I kind of saw um ah, the psych wing as a bit of um an asylum in the old sense of the world, as a refuge and where um, how did it make me feel being in hospital, a great relief, because I knew I'd be taken care of and all I had to do was abide...hospital was probably one of the best places for me to wake up slowly, to um you know, re-enter reality because I was trapped in my mind trying to piece together what was going on in the world.

James had experienced direct psychiatric healthcare in a hospital for depression, and only later was diagnosed with schizophrenia. Whether this constituted a failure of the psychiatric apparatus is, perhaps, a moot point. He again waited some time before diagnosis emerged.

RS: OK. Do you spend time in a clinic or a hospital?
James: Not as an inpatient.
RS: OK.
James: I've been visiting different clinics and things as an outpatient.
RS: Can you tell me about the visits to the hospital as an outpatient?
James: Well that actually that was way before I was diagnosed with schizophrenia, cause I've been diagnosed with depression from when I was very young and um, so I used to go and see a psychiatrist at the Sydney clinic um I think from when I was 15 for a long time and I was seeing them once a week for the treatment of depression.
RS: OK.
James: And that was before I exhibited any of the symptoms that were later be the basis of my diagnosis of schizophrenia.
RS: Do you feel ... did you feel that it was unfair that it took so long for them to diagnose schizophrenia?
James: No, because I felt that if my psychiatrist had given me the diagnosis straight up, I just wouldn't have believed him.

Nathan's experience with multiple hospitalisation, whilst not always pleasant, helped him face drug abuse, helping solve some of the problems of analysing dual diagnosis of schizophrenia and substance abuse mentioned earlier:

RS: *So what got you to stop the cannabis?*
 Nathan: *Um, there, was 2, actually 3 admissions to psychiatric wards.*
 RS: *OK.*
 Nathan: *Um the first two were drug induced, that is I had drugs in my system and was likely to have been under the influence of drugs while I was having schizophrenia. The first time I was admitted I was in the Cummins Unit in Royal North Shore Hospital for 3 days and then they took me to Herbert Street to detox, second time I was under the influence of what I thought was LSD and I was taken to Wyong Hospital and then East Wing at Manly Hospital and then the final time which was, hopefully the final time, was I was not taking LSD anymore, I was maybe gradually coming off pot.*

Despite such statements, Nathan had varying opinions of mental hospitals and psych wings. Such variance of opinions bears testimony to the complexity both of the hospitalisation experience and the experience of schizophrenia, as well as the problems of memory and the desire to create a narrative about significant personal experiences. Such narratives, discussed at greater length in the next chapter, would help people diagnosed with schizophrenia make sense out of a biographically critical experience. At times Nathan described negative feelings about being taken to “the East Wing” if he caused trouble:

Nathan: *I just started to notice things go missing in my room, like my prescription glasses, so I rang the police to report my prescription glasses had gone missing and my mum said “oh if you do that they will take you to East Wing” and they did.*

But later, despite this threat, Nathan came to accept, and even like the East Wing. Again, the critiques of asylums and the social control thesis may have to be tempered:

Nathan: *East Wing was OK, there was a lot of different patients that I came into contact with ah, some were in a far worse state than I was in, some were in better states, or appeared more confident than I appeared to be, um, we got leave, um, you know, when we got that leave we’d go down to Manly corso and we’d uh, we’d uh, get food or go for a walk, around the beach, North Head, that sort of thing. While in hospital, the psychiatric ward there was very good uh, they had a basketball court, so I could play basketball.*

In any case, Nathan’s complex account also described the contrary, negative features of hospitalisation, with echoes of Goffman:

Nathan: *So the mental hospital was clinical, they were kind of restricted entry, like you couldn’t leave when you wanted to leave, they took your mobile phone from you, they took your cigarettes from you, they kept on changing you, as soon as you got comfortable in one bed, in one ward, you’d get moved into*

another bed in another ward, it was a case of musical beds for a while there, where you were just going from one ward to another ward.

Involuntary commitment to a hospital, clinic or psych ward is a major issue, not only for the people experiencing it, but for this thesis and its concerns with psychiatry and power. Involuntary commitment is an absolute expression of power over the body and self of the patient; a blunt blow by the psychiatric apparatus and the state; a one-sided manifestation of what Rose describes as “governmentality”. Such commission raised serious concerns about the rights and freedoms of the psychiatric patient, the trustworthiness of the psychiatric apparatus and the need to balance social control with individual rights. We have also seen in Chapter 5 that Rose argues that in the governmentality of neoliberal states there may be a blurring of coercion and consent – a blurring that may prove significant in the description of contemporary power structures involving people diagnosed with schizophrenia. However, involuntary commitment does not seem to contain such shades of grey.

Peter was committed to a psychiatric ward involuntarily. Again, the defining issue lay in the fact that he did not have awareness of his psychosis:

RS: So after your severe psychotic episode, you went back into the hospital?

Peter: Yeah, yeah I went to Toowoomba psych ward for 3 weeks. I should have been in there longer but because I was very sick.

RS: Was it voluntary?

Peter: Um, it wasn't voluntary, but cause I thought that I was, I was well and ah I wasn't aware that it was psychosis.

Peter's subsequent conversation indicated that he had later achieved insight into his illness, implying that the involuntary admission and medication had been “successful”. This can also be seen as a significant moment in the formation of a new identity, as we have seen before:

RS: OK and so after you had taken your medication did you think that it was the right thing to be in the hospital?

Peter: Um, well it took a long time for the medication to kick in and uh, but uh, really ah a year or two after that I was feeling better, really.

RS: And how do you feel about your medication?

Peter: Um, not too bad. I'm on Seroquel, Abilify and Zoloft and ah, um, I'm reasonably happy with it at the moment.

Interestingly, the process of rebuilding identity in Peter's case seems to have been predicated upon successful medication, indeed a cocktail of medications. It is not an entirely isolated experience that people with schizophrenia are prescribed a number of different medications. Peter also criticises the psychiatric ward he was taken to. Again, we face the issue of whether the psych ward is the best place for a person with schizophrenia. The presence of other people with mental illness may threaten, confuse or discomfort the person diagnosed with schizophrenia, whilst the institutional structure may tend towards discipline or regimentation.

RS: And what was it like in the psych ward?

Peter: I felt very threatened because people were sort of really wanting to, to make arguments and stuff like that, they were paranoid themselves and when you put a whole lot of paranoid people together in one ward, um, they tend to get argumentative.

Following hospitalisation Peter also acquired a support worker from a local psychiatric ward who visits him, an experience not entirely unique in a deinstitutionalised environment. The network of such relationships may take the place of regular social interaction under a symbolic interactionist approach:

Peter: Richmond PRA is ah, I'm doing, I've got a staff member helping me out from Richmond PRA at the moment, she's a support worker for me.

RS: And what does she do?

Peter: She looks after me in that she sees how I'm going and tries to um, get me into work and study and stuff.

Caitlin's dominant experience of "hospitalisation" was also outside the institution itself; she was assigned a case worker by the hospital who would visit her regularly and look after her medication dosage. Such home visitation practices have been facilitated, or necessitated, by the process of deinstitutionalisation. As we have seen, deinstitutionalisation problematises historical criticisms of the asylum, and an understanding of deinstitutionalisation must come to inform our picture of coercive psychiatric power in the contemporary field of severe mental health treatment:

Caitlin: At the moment um my case manager is handling my medication like, he'll just give me a few days supply and then he will see me again and then keep doing that until I have been feeling a little bit better, but um until I'm you know, can look after my own medication.

Caitlin describes the power a hospital exercised over her, confirming the historical critique of asylums or hospitals:

RS: When you go to the hospital, do you have any power? Can you make decisions or are they made for you?

Caitlin: They usually make them.

RS: Yep. And what kind of decisions...?

Caitlin: Well they make decisions like you can have leave, or you can have no leave or you're scheduled, or you're voluntary, those decisions.

This discussion moves into the topic of scheduling – involuntary commitment to a psychiatric ward or hospital. Such commission is again a blunt expression of power by the psychiatric apparatus, although not an experience typical of all interviewees. Caitlin clearly does not like being scheduled, and it is difficult to imagine a person who would like such an experience:

RS: And do you accept those decisions?

Caitlin: I don't accept when I'm scheduled. I don't like to be scheduled.

RS: Tell me about that.

Caitlin: Because it's like you're being locked up, you've got no freedom and you know I like to go out, go for walks and things like that. And go take myself for a coffee and then come back.

Caitlin expands upon this theme later in the interview, expressing her unease at the possibility of an ambulance coming to take her to hospital, or even the police. Rose's picture of a blurring between coercion and consent again seems inadequate. We may also understand Caitlin's expression of unease as a form of resistance to the psychiatric apparatus, if not to the neoliberal state more broadly:

Caitlin: Yeah. I wonder whether the injections, um, I wonder whether that's doing any good. When you been on injection for a long period of time, your body gets immune to the medication and it doesn't work, so I'd rather be off that but they put me on a community treatment order because I wouldn't go and have it.

RS: What's a community treatment order?

Caitlin: When you're forced ... If you don't want your injection, you're forced to have it.

RS: And who made that decision?

Caitlin: Um, my case manager.

RS: And you weren't happy with that?
Caitlin: No.
RS: Why were you not happy?
Caitlin: Because I didn't want the community treatment or whatever, force me to do something if I don't want to do it. Like, they ring an ambulance if you don't go in and get your injection. And you have to go with them because they will schedule you and if he decides he can ring the police and tell the police to take you to hospital and get your injection.

Although only a few of the respondents were scheduled or otherwise forced into treatment, the experience is certainly one of theoretical, and humanistic, interest. It is of theoretical interest because it confirms the power of the psychiatric apparatus over the sick individual, and perhaps somewhat rehabilitates Rose's picture of a blurring between coercion and consent. It is of humanistic interest because it is the meeting point of individual rights to self-determination and the interest of society to control and limit that which is perceived as bizarre or a threat.

The Impact of Relapse

We have already seen a number of cases where relapse has led to re-hospitalisation. In a significant number of situations, such an illness trajectory has resulted in a positive outcome, insofar as the patient may have achieved insight into their condition or may have stabilised on a relatively successful medication regime. Like the original experiences of schizophrenia, diagnosis and hospitalisation, however, relapse can lead to disruption of one's biography and identity. As with the experience of biographical disruption in schizophrenia, symbolic interactionism as it stands may prove insufficient to give a detailed account of the specific symptoms of a dysfunctional self; an issue addressed in Chapter 9.

Some patients engaged in illness management (a concept dealt with in the next chapter) and seemed to exert control over their medication and relationship with their symptoms. Danielle, for

example, seems to have exerted a strong degree of control over her symptoms, including possible relapses and recurrent phenomenological discontinuity:

- RS: OK. Have you had relapses?*
Danielle: When you say relapse, what do you mean?
RS: Some of those bad symptoms coming back like bad thoughts coming back into your head or saying things that you shouldn't be saying.
Danielle: Yeah. They sometimes come in my mind but I try to ignore them. Yeah.
RS: And are you always able to ignore them?
Danielle: Usually I am yes.

Prescott describes coming back from relapse in some detail. His emphasis that “it takes a long time” speaks to the intensity of relapse and the difficulty of rebuilding a sense of identity, explored in the next chapter. He describes a number of techniques (such as “getting the routine started”) that become significant in later chapters dealing with illness management. His use of the term “normal life” is interesting as it implies a process, or illness trajectory, towards wellness and rebuilding a sense of identity:

- RS: And how long has it taken you to get back to yourself, your normal self, when that happened?*
Prescott: It takes a long time, it does. It takes a long time. Once they find you and they are able to help you, at the beginning, so you are talking about a short period of intensive um, psych ... psychiatry work, psychiatric work, then it takes a year to, before you are actually able to live your normal life.
RS: And what do you do during that year?
Prescott: Uh, well, I mean it's returning to work, it's returning to study, getting the routine started, earning money, being responsible, taking the meds, having insight, not missing appointments, yeah so, I think it's a sign, so, when, a sign when you're not attending your appointments that something is wrong.

Ralph describes a career of going in and out of hospital. Ralph describes re-hospitalisation and, along the way, “learning the lesson” to take his medication:

- Ralph: You know, you go overseas and you know the moment you step across the border whether it's the food or the type of coffee or um, the fashion in the street everything is of its own flavour and um, that's what happens when I become psychotic. It's that everything has that flavour of psychosis and um ah I don't know whether this is applicable, but um I came to a stage where um I'd been in and out of hospital several times um because, you know, I forgot to take my medication and within two or three weeks I'd end up in*

hospital and I learned that lesson and I gotta take my medication and then on one occasion I gave up cigarettes and that was so stressful, even though my psychiatrist didn't think that cigarettes was the thing, I reckon because it was so stressful, I ended up in hospital.

Caitlin also describes the darkness of the relapse experience, a clear biographical disruption of her identity experience and ontological breakdown, with a hint of the mental toughness necessary to overcome the disruption of mental illness:

Caitlin: Yeah, that's it. Because that's the worst. I mean that's happened to me before, where I've fallen into a hole so dark and deep that you don't think you'll ever get out of it. But you do.

RS: How do you get out of it?

Caitlin: With treatment, mainly with a lot of support and yeah, like when you are in hospital, you have the nurses to talk to, you have the psychiatrists to talk to and yeah.

It is perhaps surprising that people should emphasise the positivity, or construct a positive narrative out of, their illness experience, especially after relapse or re-hospitalisation. For example, out of the darkness of relapse Caitlin had emphasised a somewhat positive experience. Perhaps such stories, beyond the mere fact of probably being true, provide self-esteem and hope to the narrator. The role of hope is dealt with in a later chapter:

Caitlin: It's interesting because as I said years ago, I used to be withdrawn all the time and not be able to speak and hold a conversation and things like that but now I can. (pause) I've learned that, you know, to express my feelings and how I am and how I'm doing and things like that. I've learned over the years to do that. Through a lot of help I've gotten and support I've gotten.

Peter also experienced relapses, though retained the acumen to call a mental health service – a necessity in a deinstitutionalised mental health care environment and one where care for the ill has been devolved from a neoliberal state:

RS: Tell me about your relapse or relapses.

Peter: Um, well I've had relapses even when I was here, I was worried that the bikers were out to get me and stuff like that. I was paranoid and locked myself in and all this sort of things. Um I've had relapses like that.

RS: OK and do you end up in a psych ward?

Peter: No, no, I tend not to because I go to um, mental health services ... there's a mental health service ah I tend to ring them up and I have appointments with them and so forth.

RS: And what, how do they work?

Peter: What happens is that you ah, more or less report in and you tell them your symptoms and all that sort of thing then they book you in, talk to the relevant person and then they, of mental health, and then they get in contact with you and you go in and see them every week or second week for about 3 months or something.

RS: And does that work well for you?

Peter: Yeah, yeah it does and um then they discharge you at the end of the 3 months or whatever and ah until you have another relapse and then you go through the same process. That's why I don't end up in hospital because I tend to um do the mental health um [pause] go through the mental health line and then see a um, a mental health worker.

Analysis and Emergent Themes

At this point we may begin to draw together some of the theoretical and analytical threads of the thesis. We may reflect on the research data results presented, and begin to explore how such results impact upon, confirm or upset the theory outlined in the Theory Chapters.

Perhaps the most significant theme to emerge from the data regarding schizophrenia and identity disruption is the sheer scale of disruption many interviewees experienced as a result of illness, diagnosis, hospitalisation and relapse. Interviewees spoke of change of identity; of becoming another person. Prescott, for example, spoke of being one person in late adolescence, being a different person during psychosis, and being a combination of the two after medication and stabilisation. Others spoke of intense symptoms that threatened their identity. Ralph, for example, told a personal story that reminded one of fragmented, divided and lost selves; psychosis as an “I am” illness. Such change seemed to have happened at all points on the illness trajectory – the initial impact of schizophrenia was severely disruptive; Ralph talked about entering the “land of psychosis”. Diagnosis confirmed for many the importance of their illness. Hospitalisation was greeted often with

mixed feelings but, in at least one occasion, convinced the interviewee that he was indeed sick. Finally, relapse occurred as an experience that could reignite the disruption of schizophrenia.

This type of disruption certainly constituted a “biographical disruption” in most cases. In fact, it would be fair to say that in many cases the disruption of everyday life and self was intense enough to merit an intensification of the term biographical disruption; an ontological shock or breakdown had occurred. Interestingly, a sub-theme emerged around the fact that a small number of people experienced their diagnosis or hospitalisation as a positive experience, one that helped them to develop as a person. Such development somewhat complicates our picture of identity disruption.

The second significant theme, or strand of analysis, surrounds the issue of using symbolic interactionism to account for identity disruption in people diagnosed with schizophrenia. Certainly, as we will see, symbolic interactionism provides a strong theoretical model for understanding the rebuilding and maintenance of identity. But what about accounting for an identity that is dysfunctional? Disrupted? Undoubtedly, the symbolic interactionist model points to the importance of a lack of interaction in the breakdown or ongoing compromise of identity. The model also emphasises the need for internalising the view of the general other in avoiding identity breakdown. However, symbolic interactionism simply does not account well for the nature of dysfunctional selves; it is a model geared towards describing “healthy” self processes. It does not account, for example, for paranoia or a sense of persecution. This is perhaps a problem for sociological accounts of identity more generally. This problem is here magnified by the fact that symbolic interactionism cannot clarify the existence or significance of particular symptoms that a person diagnosed with schizophrenia may experience. In light of this problem, we must seek to remodel symbolic interactionism to account for “compromised” gestures and interactions that occur in schizophrenia; such a project is attempted in Chapter 9. However, the problem also emerges in a slightly different way through the inability for symbolic interactionism to account for the impact of interviewee’s

emotional states – states such as agitation, anger and aggression, as well as despair or hope. Symbolic interactionism is a perspective that focuses on thought and meaning, not emotional content. Likewise, the embodied nature of many symptoms of schizophrenia escape symbolic interactionist description. In light of this problem, Chapter 9 also attempts to outline a role for emotion and embodiment in symbolic interactionist theory.

It is at this point that we may note the uses of phenomenology in describing symptoms of schizophrenia. Identity disruption over the schizophrenic illness trajectory may be said, in most cases, to constitute a phenomenological breakdown. This reinforces the observation above that schizophrenia seemed to often constitute an ontological breach. The central phenomenological concept of “body-in-the-world”, borrowed from Merleau-Ponty, provides a flexible tool to account for sensory dysfunction, delusion or hallucination; such experiences can be understood as a breakdown of the body-in-the-world. Binswanger’s “breakdown in the consistency of natural experience” also seems to capture the experience of a number of interviewees. Minkowski’s description of “loss of vital contact with reality”, as well as his concept of “poor autism” and Sass’s account of negative symptoms brings subtlety to symptom description. Indeed, the close, personal focus of the phenomenological approach responds well to the call for study of schizophrenia from the point of view of those diagnosed with it.

Moving beyond the impact of symptoms, and their description, the data presented here suggests that diagnosis was in fact an important turning point in the illness trajectory of interviewees. The diagnosis did often contribute to disruption of identity and impacted upon biography. Some respondents even received their diagnosis with relief; it made sense of a disordered experience. Michael, for example, spoke of his mind being “released” by diagnosis. The emphasis on diagnosis also generally affirms Foucault’s analysis of the power of the psychiatric apparatus. Such power is evidenced in the impact diagnosis could have. It was also evidenced in the fact that a number of

people were content with their diagnosis, even if it arrived a significant period of time later than the initial impact of the illness. Interviewees also generally trusted their psychiatrists making a diagnosis that could severely affect their lives. Similar opinions expressed by Charmaz and Hayne regarding the significance of diagnosis were also confirmed.

The data in this chapter also provides a number of interesting lines of analysis that relate to issues of power and social structure. As noted in Chapter 5, hospitalisation is no longer a long-term or life-long treatment option for most people requiring mental health care. This fact was certainly confirmed by the data. Sufferers no longer experienced the degradation of the total institution; they no longer experienced seriously institutionalised identities. These facts, of course, are largely explained by the historical process of deinstitutionalisation and the emphasis on care in the community sector and at home rather than by the state (as Rose suggests). It is a sad aside that many people with schizophrenia, and many interviewees, suffered significant isolation under the policy of deinstitutionalisation. Isolation was, in fact, a pervasive theme, and will re-occur in upcoming Results Chapters. However, even in a deinstitutionalised context, interactions involving power still occurred in psychiatric clinics or wards for the (relatively) short period interviewees spent there. Interviewees spoke of having choice taken from them; of being kept with other mentally ill or paranoid people. In Foucauldian terms, hospitalisation, as well as medication, helped produce subjectivities that were “docile” and could be medicated and released back into the community. However, some interviewees also spoke of hospitalisation as an “asylum” in the protective sense of the word. The clinic became a place where sufferers could gain insight into their illness; where they could rehabilitate; where they did not have to face the vicissitudes of mental illness without support. Such contrary themes point to the fact that the role of the hospital, clinic or ward is a complex one.

This complexity of experience was further confirmed by the role of coercion, consent, negotiation and resistance by interviewees against, or with, the psychiatric apparatus. Rose’s observation that

coercion and consent were blurring under the project of governmentality in neoliberal states emerged in some of the data; some interviewees spoke in mixed terms of their commission and the processes of the psychiatric apparatus. Caitlin, for example, adopted an ambivalent tone towards accepting her diagnosis. Likewise, the theme of negotiation with the psychiatric apparatus occurred. A number of examples emerged where interviewees negotiated their medication with their psychiatrist. Resistance also emerged, particularly in the negative experiences of involuntary commitment reported by some people. Such experiences of negotiation and resistance affirm Foucault's observation that all exercises of power or power/knowledge necessarily imply a certain resistance on the part of the weaker party. Indeed, negotiation and resistance were perhaps more common themes than a reading of Foucault might suggest, since the disciplinary power of the asylum as institution is compromised by the ability to negotiate and resist. Such compromise, such complexity in the exercise of power by the psychiatric apparatus, will come to form a significant theme in Chapter 9 where we seek to move beyond a Foucauldian conception of the power of the psychiatric profession.

Whilst negotiation and consent occurred in many circumstances, it is important to note the few situations of involuntary commitment or treatment spoken of by interviewees. Such commission represents a blunt exercise of power over the body and self of the patient by the psychiatric apparatus and the state; a one-sided expression of the dominance that the psychiatric apparatus still has in extreme circumstances. Here, there is no blurring or coercion and consent and there is no effective resistance. Interviewees clearly did not appreciate involuntary commitment or treatment. This theme resonates with the social control thesis explored in Chapter 5. It is indeed an important question raised by this thesis – when and in what circumstances can involuntary commitment be justified? Where do we find a balance between individual rights to freedom, community interests in safety and medical interest in treating pathological states?

Finally, some data in this chapter touched on themes to be explored in following chapters: in particular, the importance of illness narratives, the use of psychiatric language, the use of the term “consumers” and the importance of insight for rebuilding a sense of identity. The thesis now turns to data relevant to rebuilding a sense of identity.

CHAPTER 7

Results: Rebuilding Identity

This chapter presents material relevant to schizophrenia and rebuilding a sense of identity in light of, and after, identity disruption. Unfortunately, not all interviewees seemed to have rebuilt fully viable, independent senses of self and of identity. Nevertheless, most people, for the most part, had established some significant self-identity in the Meadian sense – they were generally able to exist in a social world, could project themselves and their communication into that world, and had the ability to see themselves from the perspective of others.

The chapter begins with a recognition of the ubiquity of medication as a means to minimise, if not remove, symptoms of schizophrenia. Medication is essentially the basis upon which respondents could subsequently build a successful identity (although there are some ongoing debates about the value and efficacy of medication that are not dealt with here). Perhaps not surprisingly for research based upon semi-structured interviews, the significance of “illness narratives” also appeared as a means for sufferers to make sense of and shape their experience of identity disruption. The importance of language also became apparent with the use of psychiatric terminology by respondents to describe their illness situation. As we will see, the term “consumer” is particularly significant in this regard, connecting the respondent to a conception of mental health services as a market product. From there, the symbolic interaction and self-esteem provided by family and friends, as well as paid or unpaid work, surface as significant factors. The terms “illness management” and “life management” are used to capture the various active and practical behaviours respondents engaged in to help rebuild disrupted lives. Finally, the role of religion,

though not universal, also arose as a factor helping isolated individuals to re-connect to friends and community, as well as provide a more general source of meaning in life.

On the Scale of Rebuilding a Sense of identity and the Uses of Phenomenology

Before diving into the data relevant to rebuilding a sense of identity, it is worth noting that, just as identity disruption proved to be highly significant and intense for people diagnosed with schizophrenia, so too the process of rebuilding a sense of identity is significant and difficult. Just as the person diagnosed with schizophrenia must face a biographical disruption, if not full-scale crisis, so too must the person in recovery reconstruct a personal biography carefully and fully. Just as diagnosis and hospitalisation involved a fundamental change or challenge to identity, so too must the recovering patient attempt, sometimes in vain, to reach the functioning of a pre-illness self. And just as the entire illness trajectory of schizophrenia may create an ontological crisis, so too must the person diagnosed with schizophrenia reconstruct the ontology of his or her being.

Perhaps at this point, whilst the issue of ontology is mentioned, we may consider the role phenomenology may play in describing the process of rebuilding a sense of identity. Put briefly, we find that, for all its power to describe the emotional and embodied symptoms of schizophrenia, phenomenology falls short of offering a strong account of how those symptoms may be relieved or removed. The concept of compromise of body-in-the-world makes sense of certain aspects of identity disruption. However, phenomenology does not present us with complementary concepts to make sense of the process of rebuilding a sense of identity. It will be an important task of Chapter 9 to investigate what such concepts may resemble. We may start this task here, however, with the two observations that such concepts will in all likelihood draw upon processes further described in this chapter and will probably need to account for the diversity of the illness experience.

Medication

The use of psychiatric medication emerged as one of the most important and almost ubiquitous tools used by people diagnosed with schizophrenia to reduce symptoms and re-build a confused or diminished identity. The medication typically helped by reducing the intensity of symptoms that threatened the respondent's sense of identity and thereby accelerated the process of rebuilding a sense of identity. Of the 12 people interviewed for this thesis, 11 emphasised the importance of medication. The one respondent who did not emphasise her medication (Gale) did not seem to have insight into her symptoms; she suggested repeatedly during the interview that a prominent member of a university in Sydney was trying to kill her and that she received psychic visions.

As evidence of the importance of medication, it is easy to point to the fact that the majority of respondents were able to both name their medications and communicate their dosage with a fair degree of accuracy. This intimacy with medication suggests the colonisation of psychiatric practice by the psychopharmaceutical companies that manufacture anti-psychotic medication. Many interviewees take an active interest in providing feedback to doctors and controlling their medication intake. This expression of independence becomes significant in the later Chapter 9 where it presents a form of negotiation or resistance to the psychiatric apparatus. Such negotiation or resistance will form a significant part of the attempt to move beyond a Foucauldian theory of power exercised over those with severe mental illness. An example of such feedback lies in Nathan's outline of his drug regime and his discussions with doctors regarding his medication. Nathan's account is also significant because it reveals a possible negative side to taking psychiatric medication, and a more nuanced relationship between medication and re-establishing a sense of identity. Medication may certainly help reduce symptoms, and hence re-establish a sense of identity, but often fails to clear the respondent of all symptoms and leads to significant side-effects:

Nathan: I've always been totally compliant with my medication, except in a situation like with Seroquel, sometimes knocks you around a bit and you feel like you could sleep for 3 days. Like 3 days continuously.

RS: Yeah.

Nathan: And then you have to wake up and take it again and you say "Look I'm already quite affected by it, I'm still very tired" so in some cases, the doctors don't get it, the doctors don't listen to my feedback regarding side-effects of medicine, they've lowered my Seroquel dosage as well and they've just recently lowered my Paliperidone injection to 75 mgs thinking that maybe as I have been sober off cannabis that maybe I don't require as much anti psychotic medication now.

Sally names her drug regime. Sally also makes a comment, almost an aside, about losing her children – “When I lost the kids”. It would seem likely that the loss of one’s children would be a highly disruptive and upsetting experience:

Sally: When I lost the kids I was taking Anatensol but um I'm now taking Effexor and um, Zyprexa.

What is the significance of this for the themes explored in this thesis? Perhaps we may observe that symbolic interactionism must recognise the important emotional attachment a social actor has to particular others. That is to say, when the social actor interacts with others, they will evince a closer emotional connection to some. Presumably the closer connections will provide more significant feedback. The issue also corroborates the observation made in the previous chapter that symbolic interactionism does not account well for the emotional and embodied nature of symptoms and, as we now see, the emotional process of rebuilding identity.

Often respondents were taking a cocktail of drugs, some to reduce the side-effects of others. Again, medicine can play a complex role in the re-establishment of sense of self. Arthur is also able to name his medications, and is ruminative about his complex medicine regime:

RS: Did they put you on a drug regime?

Arthur: Oh, very heavy stuff, you know, Diazepam, stelazine, some other one, what was that other one now, something to cut the side-effects of the Stelazine, I

can't remember the name of it now, so you know, yeah, it was just a drug to cut the side-effects of the heavy dose of the Stelazine, I don't know if you've even heard of Stelazine, have you? Well, it might have been phased out by now, that's a long time ago, you know. Diazepam is another name for Valium, you've probably heard of that, I guess.... Diazepam I think is the medical name for it, isn't it? I used to be on a heavy dose of that and a heavy dose of stelazine and then there was - Cogentum - that's it, yeah, I think that's it, and it was a drug given just to cut the side-effects of the selazine which caused you to slow your speech and make you shake if you didn't take the Cogentum, I think.

Michael emphasises the importance of medication to his stability:

*RS: OK and you started taking medication?
Michael: Yeah, Risperidone and then a whole heap of other ones ... I'm on Clozapine the moment, this is really good, that's been working for me for about 7 years now, so I'm stable.*

It is also important to note that respondents sometimes built their sense of identity around the fact of their medication. Indeed, for some interviewees their medication *becomes* their identity. Prescott goes so far as to affirm that it is “part of my identity”. This, as we shall see, indicates the importance of medicine from a broader perspective of identity creation, and the power of the psychopharmaceutical complex. The emphasis placed on medication to heal dysfunctional processes of brain chemistry implies that the self is not only amenable to medication, but in fact that the self arises out of a neurochemical process in the brain; as predicted by Rose, a “neurochemical self” arises. The emphasis on medication also implies that the process of rebuilding a disrupted identity or self relies upon correct medication and in fact necessitates the existence of the psychopharmaceutical complex. Psychopharmacology has colonised not only psychiatry, but the recovery process and the very self of the patient:

*RS: And do you still feel like you are schizophrenic?
Prescott: Ah, yeah. Cause I take my meds everyday and ...
RS: ...so it's really part of your identity?
Prescott: Yes, it is part of my identity.*

Danielle relates a story of the “lesson” she learnt about stopping her medication. As we have seen in the previous chapter, similar stories have been told by respondents who stopped their medication and suffered relapse:

Danielle: ‘cause the times when I tried to get off the medication I felt like I didn’t need the label and I felt like I could just do it on my own. But then it’s like I was proved wrong or something and I had to go back on the medication.

Perhaps it is not surprising Danielle would reject her medication. Typically anti-psychotic medication has mild to severe side-effects. Indeed, Danielle was unhappy with the initial psychiatric control of her drug regime, especially as she seemed to exercise no choice over her medication. Such unhappiness often comes to form a resistance to the power of the psychiatric apparatus. Examples of resistance such as this complicate the “one-way” picture of social control being exerted by mental health workers and psychiatrists over patients. Resistance and negotiation of treatment will become a significant issue in Chapter 9, where we seek to move beyond the Foucauldian conception of power exercised by psychiatrists and the psychiatric apparatus. Resistance again emerges in the words of Danielle:

RS: And did you have any control over which drugs you would take?
Danielle: No.
RS: How did that make you feel?
Danielle: I was a bit upset and angry.

Peter also emphasises the “lesson” of “taking his meds”:

Peter: And then went through a very severe psychosis and then after that, I very slowly got well, but, I’ve never ah, I’ve always stuck to my medication from then on and that tends to be the reason why I don’t go to hospital these days.

Unlike some respondents, Peter had some control over his medication intake; asserting his identity through an exercise of negotiated power with his psychiatrist. Such exercises again become relevant in Chapter 9:

RS: Do you find the doctors respect you?

Peter: Um, they tend to, they tend to be respecting, although in one sense, in one sense ah, they tend to try and put you on Clozapine and all this sort of stuff and I always have to say no to it?

RS: OK, why do you say “no”?

Peter: Um Clozapine is ah, although it’s a good drug for your illness, it can have very severe side-effects, can have, and so you gotta have blood tests every second day, or every day for a month or something and so and then every month after that, so, you know. I’m not all that keen on Clozapine.

Greg took a variety of medications, but still experienced symptoms that led him to have a negative outlook upon his identity:

RS: How do you feel about your medication?

Greg: [...pause...], It probably helps me but I don’t think very much. Yeah.

RS: So, why does it not help you very much?

Greg: Because I still have symptoms.

RS: You still have symptoms?

Greg: Yeah. I’ve sort of given up on life. I’m not gonna commit suicide or anything, but I’ve just lost the spirit.

The ubiquity of medication as a therapeutic tool and the acceptance of psychiatric medicines by patients and psychiatrists points to an important point made in Chapter 5 of this thesis – that the psychopharmaceutical industry has “colonised” psychiatry, and especially the psychiatry of schizophrenia. One may certainly say that this has happened because of the relative success of medication in reducing psychotic symptoms and allowing a sense of identity to re-emerge. However, these medications are not successful in all cases. Indeed, it is probable that interviewees for this thesis had more successful outcomes with their medication than many people diagnosed with schizophrenia; these interviewees were probably at the “better” end of the illness spectrum, with less severe symptoms, an ability to communicate despite the presence of symptoms, and a degree of insight into their condition. It would be a difficult task to gather relevant information from people in the midst of psychosis, or otherwise lacking insight.

We end this section with an interesting quote that makes a connection between the taking of medication and the social control of people behaving bizarrely. The comment tends to support the thesis that treatment of schizophrenia is primarily an act of social control and is significant coming from a person who is diagnosed with schizophrenia. Here Rose's argument about the blurring of coercion and consent in contemporary governmentality seems apposite:

Ralph: I suppose by being on medication I've given up some ownership of my own responses by being medicated for the benefit of others in society because I can't exist, you know, in a psychotic state for long because it's so, my world, reality is so fragmented, um and I think that, you know, if social cohesion um is necessary at the cost of medicating some individuals in society um, you know, not that that question ever appears but I kind of think that um in one way its required for social cohesion to exist, um if people were to be medicated, maybe it's necessary.

Illness Narratives

Another tool used for the rebuilding of identity after the disruption of schizophrenia and its attendant institutions was the creation by respondents of narratives that "made sense" of their illness. Such illness narratives were discussed in Chapter 3 as a form of symbolic interaction (see Williams 1984; Strauss and Corbin 1987; Corbin and Strauss 1991; Bury 2001; Locock et al 2009). Illness narratives turn the experience of mental illness into a story that might be told to relatives, friends, or mental health professionals. This story typically describes the patient's pathological experience and plots his or her illness trajectory towards well-being. These stories can be important tools in helping the patient understand and grasp (or construct) the meaning of their experience with schizophrenia, as well as healing the temporal breach of biographical disruption. In this sense, illness narratives emerge as a natural response to biographical disruption. And, just as biographical disruption can sometimes become crisis, so too must these narratives bear the weight of rebuilding identity to a pre-crisis level, a task at which they do not often succeed. At the same time, these stories can bear witnesses to reversals or relapses in a patient's condition, and there would seem to be a variety of possible narratives amongst respondents.

As seen in Chapter 3, Bury describes “contingent”, “moral” and “core” narratives co-existing in the patient’s dialogue. To return to Bury’s account, contingent narrative is one that:

address[es] beliefs about the origins of the disease, the proximate causes of an illness episode, and the immediate effects of illness on everyday life (2001, p. 263).

The moral narrative is one that:

provide[s] accounts of (and help to constitute) changes between the person, the illness and social identity, which help to (re)establish the moral status of the individual or helps maintain social distance (2001, p. 263).

The core narrative is one that:

reveal[s] connections between the lay person’s experiences and deeper cultural levels of meaning attached to suffering and illness (2001, p. 263).

These narratives may have a “stable”, “progressive” or “regressive” quality: a stable narrative is one where the speaker remains on a stable trajectory regarding his or her illness; a progressive narrative is one where the speaker has made or is making positive progress with their illness; a regressive narrative is one where the illness is worsening.

The effect of these narratives has been described as “biographical work”. At this point it is important to point out that biographical work through illness narratives typically takes the form of a narrative communicated from one person to another. In this sense, it confirms the symbolic interactionist principle that developed communication between peers lies at the heart of self and identity. It is fair to say that many of the respondents had some form of narrative, however tenuous or fragmented, around their experience of, and return from schizophrenia. However, some respondents seemed to resist turning their experience into a narrative, as we shall see. It is also important to note that the creation of such narratives forms part of the concept of “identity work” suggested in Chapter 9.

Of the respondents interviewed, two – Prescott and Ralph – had strong positive illness narratives.

Prescott’s narrative of wellness can best be described as “moral” with a “progressive” quality. It

began with independent research into schizophrenia:

Prescott: Yes, so I started with that, and I started reading books about Surviving Schizophrenia; I think was one of them, um and there are a couple of other books and I wrote down what I explained ... what schizophrenia was, so I don't have that with me today, but it was about a paragraph or two, explaining about delusions, a racing mind, the snap system, the neurons working quicker than they would in a normal person, um, creating delusions, understanding being completely um .. to contain and completely believable, the delusions, completely believable, so it just explaining that to originally, I used to explain it to a close friend of mine, a girlfriend and she sort of had a bit more insight into what was going on in my life as well as what she thought was schizophrenia was about. So, all of those things have meant that I've had to do some sort of study into working out what schizophrenia was about.

As we shall see in Chapter 9, progressive narratives, like this one, are very important from the view of language use, power and agency in people diagnosed with schizophrenia. This is because the narrative involves the narrator as the natural “agent” of the “story”, focusing on key moments of personal transformation or insight on the path to wellness. This, in turn, complicates a model of recovery posited centrally around medication without change of the sufferer’s social situation, and qualifies the picture of one-way power exerted over people diagnosed with schizophrenia.

Prescott further related the new difficulty of achieving previous goals when asked about his diagnosis and goal setting. This narrative seems to have a different tone; a “stable” quality – dissimilar to the previous narrative quoted. The co-existence of different forms of narrative within the same interview occurred in a number of respondents, attesting to the complexity, even contradictory nature, of the narrative process:

RS: And how did you feel when you found that out?

Prescott: Um OK. I felt fine about it, my issues were being managed, and I understood what they were explaining to me about the course of medication I needed to be on.

RS: How did this make you feel about yourself?

Prescott: A little bit disappointed. Um. I had, you know, great ambitions to be someone and to have a condition like schizophrenia ... had been expressed to

be the truth of my outlook on life meant that I was going to have more problems getting to that sort of stage of my life where I'd reach those goals that I was setting.

RS: What kind of goals were you setting?

Prescott: At the time that I was diagnosed?

RS: Yes.

Prescott: They were finish university, they were looking after myself with some sort of job and some sort of, you know, family life, girlfriend etc, that sort of thing. So those sort of three aspects of it and the way I understood mental illness was that this was going to be harder for me to get to that stage that other people sort of take as a general step in their life.

In the end, however, Prescott strikes another positive, “progressive” note:

Prescott: I have to accept it and that's one of the things of the condition, that, I try and improve myself so I accept it but whilst I've got the ability to move forward, I've got the ability to apply myself to new things and try my very best to find a way of learning things considering I've problems remembering specific details.

Prescott echoes this note later in the interview:

Prescott: [H]aving a condition that is being capable of being managed and gives you a chance to a normal sense of life is great, considering where I've come from. That delusion, that psychosis, that irrational behaviour, confused thinking, so um, certainly, definitely, having the condition managed, having the managed condition.

Prescott's description of “having the condition managed” recalls Rose's characterisation of governmentality in neoliberal states as a phenomenon where people are encouraged to “reconceptualise themselves in terms of their own will to be healthy, to enjoy a maximised normality” (Rose, 1996b: 52). More on “maximised normality” will be said below.

Ralph began his interview with a lengthy description of his life before schizophrenia, the pro-dromal phase and his diagnosis. These may fairly be described as a “contingent” narrative and, at this point, “regressive”. The narrative, though winding, is certainly intense and clearly personal, including an admission of a suicide attempt. In one sense, suicide is the ultimate negation of identity; the end of biography; the ultimate biographical crisis. As noted earlier, a significant number of people diagnosed with schizophrenia attempt suicide; an indication of the difficulty of certain schizophrenic symptoms and side-effects of medication. Another interesting issue raised again by this narrative is

that of agency; that is, the narrative does not portray Ralph as the agent of changes made in his life, except for the decision to attempt suicide. It is an uncomfortable thought that a person may be so entrapped by their illness or situation that suicide presents the only available act of personal agency.

Again, we may also point out the importance of such issues of agency in the analysis of power in

Chapter 9:

Ralph: So two guys I was staying in Adelaide with, Quinnie and Dave, Quinnie was leaving back to Sydney and Dave was moving to Melbourne and um, they said "what are you going to do" and um I said "I'm probably going to stay in Adelaide" because I couldn't make a decision and um ah, I started getting really quite paranoid um, you know thinking conspiracies um thinking um unseen [pause] decisions and um movements and um orchestrations was happening in lieu of my ability to connect with the world and um, ah, that increasingly got worse and I remember working in the um, petrol station and just in my own mind creating up stories about who was coming into the petrol station and, you know, based on their demeanour, what they looked like, what kind of car they drove, how they, you know, interacted with their environment and um. [pause]. So my friends were leaving Adelaide and I had to make a decision what to do and um, I couldn't make a decision and I remember my room was increasingly becoming messier in that I couldn't keep order and it was deteriorating and becoming quite rubbished, like I kept it clean but there was no order and um [pause] my mate, Quinnie, rang my parents and said "listen, we're" - that's better - um my mate, Quinnie um rang my parents and said "listen, something's up with Ralph, we've gotta do something, um I think you're best to come down to Adelaide and um, ah, suss him out" so they flew to Adelaide, booked into a hotel, rented a car, came around and saw me, made the decision that everything was to be chucked in the back of Quinnie's removalist van and be shipped to Sydney and I flew out about 3, 4 days later and I was at home for a week and then they took me to my local GP and um, he was a bit concerned, I think but again, you know, I think at this stage I was having a breakdown, an acute episode and um ah I was at home for a week and had a suicide attempt um ah during that time which I didn't tell anyone for probably about 10 or 15 years, um and then [pause] obviously it didn't work and um the next, probably 2 or 3 days later my parents thought to get me out of the house, cause they weren't sure what to do and, you know, because I was so uncommunicated [sic], I was kind of catatonic, I was thinking, you know, I was trying to work out reality that it was like I was suffering the incapacity to understand what was going on with the world. Um and um, you know, it was very distressing and I think that was why I tried to take my own life whereas because of the distress.

Ralph moves on to describe the impact of diagnosis as a positive, "progressive" narrative; such reversals in narrative again attest to the multifaceted nature of narratives of rebuilding in a number of respondents. Here the sense of Ralph as the agent of his own narrative is stronger:

Ralph: You know, part of um, I think, you know, I was really gung ho before I had my diagnosis and I think my diagnosis caused me to become a lot more reflective um, um it caused me to become a bit more, I wouldn't say intuitive, but you know, listen, listen to my conscience a bit more um, it certainly caused me to be a lot more compassionate towards others um. It subsequently caused me to, you know, if things aren't going my way, um look to what's going on for someone else, um and think well, you know, life's inherently messy and, you know, maybe what I'm doing is upsetting the other party unbeknownst to either of us.

Despite the significant impact illness narratives seem to have, a few respondents resisted the urge to give an expansive account of their illness. Danielle offers a short, ambiguous narrative at the end of a number of questions. The use of narrative was not an ubiquitous tool for self rebuilding. Some interviewees seemed to prefer not to focus on their illness experience:

RS: Do you remember what that medication was?

Danielle: No, I don't remember.

RS: And were you happy to take that injection?

Danielle: Half and half.

RS: Half and half, why was that?

Danielle: I don't know why, I just, I don't know, half I was sort of glad to just maybe forget about all the past and half I didn't like it because I didn't like the fact that I was being diagnosed or something.

Michael likewise offers an abbreviated account of what would seem to be a serious, unsettling experience.

RS: [C]an you tell me the story of your illness?

Michael: [pause] no story to it really, just that I felt sick in 2002 um, I was taken to Maitland Hospital, I had a psychosis attack in hospital and they um reviewed it and then they put me on medication and I've been on medication ever since.

RS: What happened during the psychosis attack?

Michael: Screaming and yelling, um.

RS: Were you experiencing hallucinations?

Michael: No, just, um [pause] ... do you hear hallucinations?

Finally, it must be observed that a number of respondents emphasised the fact that their mental illness derived from a "chemical imbalance" in the brain, or other aspect of brain chemistry. For

example, Caitlin makes clear below her understanding of the relationship between schizophrenia and brain chemistry. This emphasis is highly significant. It implies that the person diagnosed with schizophrenia understands their illness as a biochemical event, process or structure. This in turn brings with it a certain degree of reduction; a belief that the illness is deterministic and the sufferer cannot interfere except to take medication. Such a belief pushes against the general direction of this thesis, which assumes that sociological factors are in fact important, if not vital, to understanding recovery processes affecting people diagnosed with schizophrenia. This belief also in turn emphasises the need for psychopharmaceuticals and the psychopharmaceutical complex that produces them. Finally, such a view casts the individual sufferer as holding an identity determined by neurochemistry; what Rose describes as a “neurochemical self”:

- RS: What was it like having the symptoms of schizophrenia?*
Caitlin: I know it's a chemical imbalance in the brain ... I know that much and um (pause)
RS: If you were talking to someone who didn't know anything about it, what would you say?
Caitlin: I would say it's a chemical imbalance in the brain and that, um (pause) people with schizophrenia do hear voices.

Prescott makes a similar significant connection between the illness, brain chemistry and medication:

- RS: Do you think that you are schizophrenic?*
Prescott: Yes, Yes I do understand that because I think one of the important things was them explaining the physical nature of the illness, the way the brain works and the way that the drugs have like chemicals that are absorbed by the brain and that helps you bring you to a stage of normality so I think the best way about it is to explain the physical parameters of what's going on, I think that's one true way.

Likewise Gale, who was diagnosed with schizophrenia 21 years before the time of interview, emphasises the link between the illness, brain activity and her diagnosis as a person with schizophrenia, or schizoaffective disorder.

- Gale: I'm just seeing a psychiatrist to get medication and I do see medication as sort of therapy for my schizophrenia and sort of regenerating my brain so that, so since then I and um, I didn't really ask about my diagnosis but I got a*

letter for a medical certificate in uni um saying I was schizoid effective [sic], so that was when I first realised it was schizophrenia.

Psychiatric Language and "Consumers"

Another important technique used by a few respondents to make sense of, and perhaps provide distance from, their illness was the adoption of psychiatric, or semi-psychiatric, language to describe their situations. Like the use of narratives of rebuilding just examined, or the naming of medications, the use of this language may form an important part of giving people a sense of control over their illness and, as such, contribute to the rebuilding of their identity. This practice is also significant because it evidences the deep control the psychiatric profession has over the naming of illness, diagnosis, treatment and hospitalisation of sufferers who come to them, as well as the influence of the DSM series over psychiatric terminology.

James describes the experience of multiple diagnoses using psychiatric language – an experience that is somewhat confusing and would probably provide an ambiguous point from which to re-build a sense of identity. The subtleties of diagnosis emerge here; the fact that James was diagnosed with schizoid personality type as opposed to simple schizophrenia attests to the idea of a schizoid spectrum, rather than very clear and specific illness categories. It also confirms Foucault's insight that the use of psychiatric discourse goes hand-in-hand with the power of the psychiatric apparatus and, in particular, the psychiatric profession to decide on and then change a diagnosis:

James: Well, um, he [the psychiatrist] diagnosed me, he didn't actually diagnose specifically with schizophrenia, he diagnosed me with a thing called schizoid personality type. Now, that's not schizo-personality disorder, it's something else. But since then I haven't been able to find, like, that guy retired in, at the beginning of, somewhere early after the year 2000 and I started seeing a new guy and the new guy hasn't heard of the diagnosis of schizoid personality type. So now I'm just under the plain schizophrenia diagnosis.

Danielle describes a similarly confusing experience. Her illness trajectory is also complicated by multiple diagnoses. Again, the nature of the schizoid spectrum becomes clear:

RS: Has your diagnosis changed at all?
Danielle: Yes, it was first just schizophrenia and then it was like depression so then it became schizoaffective disorder and now it's like still schizo affective disorder but more like the moods or something like that. I don't know exactly.

Finally, Arthur describes a long history before he was given the accurate psychiatric terms for his illness. Perhaps this history has helped him make sense of a complex, difficult experience. One can only speculate how Arthur related to the world, and himself, in the long period before diagnosis:

RS: So did the Commonwealth Medical Officer or the Commonwealth Officer explain what diagnosis, what schizophrenia meant?
Arthur: Oh no, he didn't use, he didn't tell me in these terms, this is something that I didn't discover until about 20 years later when I got all the paperwork.
RS: How did you get the paperwork?
Arthur: Well I just applied to the government to have copies of all the paperwork about me, you know and they sent it all out in an envelope, you know, about an inch thick of something and it had all the details, everything you could think of you know, what other officers in the office had said about me, all sorts of things and basically all everyone in the office had said I had been pretty hopeless for a long time, you know and even on the last day at work, they said we all wanted you gone long ago, we didn't see any hope for you and they said it was only the big boss that was keeping me there.

The result of this history was to finally receive the written diagnosis:

Arthur: I didn't know, I'd never even heard of the term until 20 years after that bloke, see, he only put it on the letter, on the bookwork, written material and I didn't get the written materials, see, I got it 20 or 30 years later when I applied for all the documents from the public service and that's when I saw the document.

A similar use of formal language lies in the application of the term “consumer” to people using mental health services. It serves to distance patients from the stigma associated with the term “schizophrenic” and the condition “schizophrenia”. At this point, however, we need to make a distinction between a person diagnosed with schizophrenia adopting psychiatric language, which

enmeshes the speaker in a web of discourse and power/knowledge, and the use of the term “consumer”, which deliberately moves beyond psychiatric discourse to avoid stigma. The use of this term also has some other important implications. The term consumer constructs the person with illness as someone essentially purchasing a saleable good; the consumer is part of the “market” for mental health “products” that Rose identifies in neoliberal states. Indeed, the movement of mental health care from the state to the community, from public right to market-based product – a process identified by Rose – impinges in many ways upon the person diagnosed with schizophrenia. Prescott illustrates use of the term “consumer”:

- Prescott: Yeah, I didn't quite, ahhh, I thought they were just completely normal people. I mean they obviously had their issues and now thinking about it, the same time (pause) yeah, it's a bit of strange situation, all the consumers together like that, because there is obviously that locked area that they don't let you in and you got to stay inside the locked area they keep you in and you have to relate to people. So, you can't just run away.*
- RS: You called them consumers?*
- Prescott: Yeah, that was what I thought as being the most recent description of somebody with my condition. A mental health consumer.*
- RS: OK and you, what do you think of calling yourself a consumer?*
- Prescott: I accept it because they feel as though that the people who run the facilities, um, I think that they feel it's the most appropriate way to call to refer to someone as a mental health consumer rather than a patient or anything else like that.*

Caitlin is a little more circumspect, but agrees with the moniker:

- RS: Do you ever use the word “consumer” to describe yourself?*
- Caitlin: A consumer?*
- RS: Yes, as a consumer of medication?*
- Caitlin: Yes, we are consumers, I think. Yeah.*

We may conclude this section with the observation that symbolic interactionism provides a supple tool to analyse language use in rebuilding a sense of identity. Indeed, the use of such psychiatric or formal language can also be understood from a symbolic interactionist perspective; that is to say, patients need to perceive their illness as an object outside themselves in order to understand and, hopefully, overcome it.

Family and Friends

One of the recurrent themes arising in the research was the importance of the patient's family. There is an extensive literature pointing to the importance of social support for people with schizophrenia (Pratt, 2013; Smolat et al. 2013; Millnera et al. 2016; Pahwah et al. 2016). The symbolic interactionist position would tend to suggest that those having a happy relationship with a supportive family and friends would be better able to move beyond their illness and engage in the process of rebuilding their identity, whilst those with difficult relationships with family would find it more difficult to manage their illness (discussed further below) and would not engage fully in rebuilding their identity. Families help provide a sense of identity in a number of ways. They can help monitor the ill person for significant changes in personality or behaviour; they can provide practical support, such as helping source medication, getting the ill person to psychiatrists and so forth; and they can help rebuilding a sense of identity after disruption through providing non-judgmental communication and emotional support. They also provide an alternative to staying in a mental health clinic or, in a deinstitutionalised environment, seeing mental health workers on some regular basis. This position, however, did not emerge in all interviews. There were significant contrary results where respondents described difficult relationships with close family members, particularly parents and children; relationships which affect the process of re-establishing a sense of identity. Indeed, a pattern of social isolation and loneliness emerged in some interviews.

This observation has significance that should be noted, not only because it is a theme that recurs in the interviews, but because it confirms a basic tenet of symbolic interactionism, that the self is formed through the process of symbolic interaction with significant others, and the generalised "other". The emotional content of symbolic interactions is dealt with in Chapter 9. This study also suggests that significant others generally include family and, as seen below, friends.

Prescott seemed to have an excellent relationship with his family. Indeed, he was living with his family and commented at one stage that he would work in the family business. The fact that he perceives his family as supportive and accepting is probably a strong factor in his positive and coherent self-presentation. It also confirms the symbolic interactionist tenet that the process of rebuilding a sense of identity relies on interactions with others. Here he describes the support of his family:

- RS: ...has having schizophrenia affected the relationship with your family?*
Prescott: Certainly. Certainly does. They've had to be very supportive and very accepting and give me all the guidance and lots of help so certainly...
RS: OK. What kind of guidance and help do they give you?
Prescott: Acceptance and love, in terms of family unit, um, they offer guidance and help when I need it, they are there when I need them, also, it's ah, it's just good to have people who care about you and (pause) through thick and thin.

Caitlin describes a situation where she had one or two friends; her existence was a lonely one. Perhaps to compensate, Caitlin spoke of her two sons and a daughter. Unfortunately her sons did not respond well to her medical state, and her relationship with her daughter was ambivalent at best. This ambiguity – the need for her daughter to “have a break” – indicates the difficulty a family may have in accepting and dealing with a relative with schizophrenia. The sufferer becomes doubly disrupted – both by the illness and by the breakdown of interactions with significant others. The situation seemed to reflect poorly upon the process of reforming Caitlin’s sense of identity; although she was by no means in a state of identity crisis, she did still report auditory hallucinations and was generally visited not by relatives but by a mental health care professional:

- RS: Do you need the support of your family?*
Caitlin: Yeah, I do need the support of my family. That's why I'm waiting for my daughter to come round, you know, um. She doesn't want to be pushed at the moment to see me and she wanted a break from me because she always looks after me, my mental health when I go and visit her and apparently it's gotten too much for her so she has to have a break and I understand that.

James emphasises the familial relationship he has with his mother – a form of life management, considered further below. Indeed, James’s reliance upon his mother in one sphere seemed to tie in with his ability to lead a fairly independent life in another, more public sphere; a highly gendered division of labour that nevertheless allowed him to present a relatively stable identity in public. With this gendered division of labour we begin to see some of the relationships of power that surround the diagnosis and treatment of schizophrenia:

James: My mum supports me a lot, um [pause] and my medication helps as well. It’s a big help.

RS: Can you tell me about the support that your mum gives you?

James: Well, I live at home and I’m not completely independent. Um, I can look after myself on my own and I have done that but I can’t do it very well and I can’t, it takes so much to do it that I can’t do that and study anymore. There was a time I could, but I can’t do it anymore. Um, so, um, she does like almost all the cooking and housework, like 99.9% of it I suppose. Um, yeah, I’m not good with cooking although I’ve made some changes recently that might help in that area. I’m not good with dishes, um, washing my clothes, I could probably do if things were organised differently but I’ve gotta walk through my mum’s bedroom to get to the backyard to hang them out so because of that, I tend to just leave them for her to do it. Um [pause] and housework, the rest of the housework, vacuuming, I’m not good at at all. Shopping, yeah, I’m pretty fine with shopping but I’m often busy with studying and stuff, so it tends to be just busyness that causes me not to help with shopping or do the shopping. Um [pause].

Danielle describes an ambivalent relationship with her parents. She claims that schizophrenia didn’t really affect her relationship with her family. However, the fact that Danielle’s mother thought Danielle was a “capable, achieving person” seems to have given Danielle confidence in her interactions – a confidence that may explain Danielle’s successful employment and clear communication. It also appears that Danielle is conscious of, if not upset by, her mother’s refusal to believe in the diagnosis. The need for confirmation by a significant other emerges as an understandable emotional imperative; a step towards the process of successful rebuilding a sense of identity.

RS: Did having schizophrenia affect your relationship with your family?

Danielle: Not really, I don't think so. My mother, she didn't like it, she, to this day she doesn't believe I have it, she always thought I was a capable positive, achieving person, successful.

We have seen a number of cases where family relationships can have a positive or negative impact on the rebuilding of identity. The reliance of respondents on their family and the results of family breakdown can be complex. Nathan describes below an episode of familial violence. The background of this violence is unclear. The event would appear to bode negatively for Nathan's process of rebuilding a sense of identity. It would seem fair to assume that family breakdown may compromise emotional stability, introducing trauma and the breakdown of interaction into the family unit. This would seem especially salient for people diagnosed with schizophrenia since having schizophrenia may force a person to rely more heavily on their family for support. On the other hand, the person suffering family breakdown may still be able to reform his or her sense of self, independent of their family. This is clearly suggested elsewhere in the interview, where Nathan expresses significant personal goals. We must also accept the possibility that Nathan's account of such violence may be delusional, or was exaggerated by Nathan's schizophrenic state. In this case, the illness itself seems to continue to disrupt Nathan's process of rebuilding a sense of identity; in particular, disrupting the symbolic interactionist process of interaction with others as a basis for rebuilding identity.

Nathan: I broke my right hand here because what happened is that my dad accused me of robbing my own house which was just totally preposterous and somehow, his face just got in the way of my hand and then I broke it and when it broke it was all jagged and they couldn't manipulate it back into place, they actually had to put a cast on it and let it heal at an inclined angle so it's never really been straight, it's always been like 60 degrees, so I get phantom pain from that and I also have an emotional pain because it was associated with my father and it was associated with his ex-girlfriend.

Later in the interview Nathan further describes his family's situation. Here the possibility of delusion seems weaker. At the same time, the extract attests to the breakdown of interaction in the family unit, and again raises the possibility that Nathan's ability to reform a sense of self may be compromised by a failure to interact positively with significant others:

RS: How is your relationship with your family?
Nathan: Oh, it's been a very difficult tightrope to walk and there are times when I feel that I'm living somewhere with my mum and with my dad and with my sister and with my half brother and then at times I feel like I have absolutely no communication with them, they shut off to me, they don't want to hear what I have to say, they don't wanna hear what my problems are.

Gale also speaks (perhaps a little confusingly) of family breakdown when questioned about symptoms. However, the relationship between apparent family violence, constant crying and reforming a sense of identity is a little unclear. It would appear that Gale's situation of violence and persecution would have acted negatively on her identity. The fact, mentioned above, that Gale seemed to have ongoing delusional beliefs regarding someone wanting to kill her, and claimed to receive psychic visions, attests to this interpretation. Again, however, we must also consider the possibility that this violence was contrived in, or exaggerated by, a psychotic state, which makes the analysis more difficult. Again, perhaps the illness continues to exert a negative influence on her ability to re-establish a sense of identity:

RS: What kind of symptoms did you have?
Gale: Well, the main thing was like I couldn't stop crying, when, like all through growing up, like people teased me and my mother hit me and my uncle hit me and then I cried all the time and they picked on me... I always clash with my mother and I always hated what she did and she always told me the wrong things to do.

Just as family was significant for most respondents' process of rebuilding a sense of identity, a few respondents reported the significance of friends too – even if only it be their absence. Friends generally allowed the diagnosed person to lead a more expansive life. And, as with families, the diagnosed person may develop self-recognition through social interaction with friends; and interactions with certain people will have a higher significance. This again confirms the symbolic interactionist position.

Ralph claims to have a “wide net” of friends – perhaps gained through his friendly manner – although he had a limited set of close friendships. This network of friends may help explain the sense of calm and self-acceptance Ralph seemed to express; perhaps it gave him perspective on his illness and life. Certainly it gives him the opportunity for rebuilding a sense of identity through symbolic interaction:

Ralph: I've got a wide net of friends but when it comes to intimate relationships I'm not crash hot on them because I get really claustrophobic very quickly and um if I'm um, I stop thinking basically and I just regress to a um what I'm feeling and I just feel claustrophobic.

Caitlin reports having lost touch with most of her friends, and focusing on her family; indeed, Caitlin lived alone and regularly met with a case worker – her situation is not uncommon in light of wide practices of deinstitutionalisation that are discussed below. That is to say, Caitlin has moved back into the community after a period of treatment in a mental health ward. A number of questions surround such treatment. Are people with serious mental illness best treated outside the clinic or ward? Would such treatment be practical or affordable? Are sufficient resources being given to community support? Finally, does the psychiatric apparatus still exercise power over the person diagnosed with schizophrenia if he or she is not in a monitored and controlled residence? With those issues in mind, we may take a more subtle view of the nature of relationships with friends and family. Indeed, Caitlin’s interview suggests that a loss of relationships with friends has led to her already-noted emphasis on family, although in the following quote, as with earlier comments by this interviewee, there seems to be some ambivalence in her relationship with her daughter:

Caitlin: No, friends, I've just lost touch with.

RS: Do you want other friends?

Caitlin: Not ... um, I'm happy on my own. I have my sons in Queensland, I have two sons in Queensland and um, I have my daughter, but um my daughter and I are not on speaking terms, so that friend that rang me up when you came to the door, he's a good friend of mine but he is my daughter's friend, if you know what I mean. And he um lets me know how she's going. Yeah.

Finally, Danielle is philosophical about an attrition of friendships. She goes so far as to say that she felt abandoned by friends, but does not suggest this was due to her illness. In any case, Danielle presented a clear and coherent self; a lack of friends did not seem to compromise such a sense of self emerging. Such a finding contradicts the emphasis in symbolic interactionism on interaction as a vital part of the process of rebuilding a sense of identity:

- Danielle: I felt like I lost a lot of friends from school.*
RS: Why did you lose your friends?
Danielle: They all went to different streams of life, you know, most of them went to study something or most of them changed schools or you know they just, I felt like they abandoned me actually.
RS: Do you feel like particular people abandoned you?
Danielle: Yeah.
RS: And do you think that they abandoned you because you were sick?
Danielle: I don't know exactly, I don't think they necessarily abandoned me cause I was sick but just maybe that's the way life is sometimes.

Employment

A significant number of respondents engaged in employment of some kind or another. This seemed to have a positive impact upon the process of rebuilding their sense of identity. Having meaningful employment also seemed a common theme amongst people diagnosed rebuilding their identity. At one level we may attribute this to employment offering a regular social interaction with others that is so important to symbolic interactionism. Employment seems to also offer other benefits. Most particularly, it seems to give some people a sense of purpose and allows them to escape a lifestyle of isolation.

This section also gives rise to questions of political economy, such as the availability of employment for the mentally ill or whether stressful work exacerbates symptoms, or the importance of “job satisfaction” as a motivator in a capitalist economy, that are outside the purview of this thesis.

However, this thesis does find a positive relationship between employment and recovery outcomes. Whether one precedes the other is unclear.

Sally, who was diagnosed with schizophrenia 18 years before the time of interview, describes having a number of occupations. The fact that she changed occupations so frequently did not seem to diminish the positive impact working had on her well-being. Interestingly, she began work in the Leisure Club, and organisation directed towards those with mental illness. This confirms Goffman's insight, explored at more length in the next chapter, that people with stigmatised conditions will search out others with a similar condition:

- Sally: Um, I um, worked [pause] um for the Leisure Club, no the first job after, um, no, yeah, that was the Leisure Club was the next job I had after it and I was casual for 3 years, um after then um, I worked as um [pause] um, selling Homecare products, door to door for about a year and then I went to this company and I was doing office cleaning and reception, um, hmmm, [pause] I was a cook for a while. In 2005, um, I went to Pizza Hut in the inbound call centre at Gordon. Yeah.*
- RS: And did you like working?*
- Sally: Yeah.*
- RS: What did you like about it?*
- Sally: The money. [laughs]*
- RS: The money?*
- Sally: Yeah.*
- RS: Did it make you feel good, personally?*
- Sally: Yeah, it was a help.*

Ralph describes some of the positive benefits of employment; in particular, self-esteem and time to rebuild his sense of self after visits to the psychiatric hospital. Such employment did not have to be complex or overly challenging – Ralph worked packing, grinding and roasting coffee. Indeed, amongst the interviewees who worked, most adopted fairly simple jobs. This is possibly explainable by a loss of cognitive ability brought on by schizophrenia. Nevertheless, employment seems to have a positive impact on processes of rebuilding identity:

- Ralph: I find work is good because it gives me an occupation in the sense that it occupies my time, you know. It gives me an opportunity to um, you know, working for 5 years in a coffee factory where all I did was, you know, pack*

coffee, grind coffee and occasionally roast coffee, for me it was quite meditative and, you know, simple tasks that don't ask much of me but at the same time allow me, um, the ability to build a bit of self-esteem on board, because I think that's what happens, every time I end up in hospital is that I lose confidence and you know, in all the times I have been back to hospital, um, every time I end up back there it takes me longer to rebuild.

Caitlin offers a similar positive account of employment, connecting personal satisfaction to “doing a good job”. She is a well-socialised unit in the structure of neoliberal economies described by Rose:

Caitlin: You have to strive you know to go to work each day, you know. But at the end of the day you, you know, that's how you do a good job, so it's all worthwhile.

Interestingly, Caitlin not only used work as a source of well-being, but also as an effective distraction from schizophrenic symptoms, no doubt helping her to re-establish an undisturbed sense of self.

Such distraction allows the sufferer the mental space to engage in a complex physical and social world, one where the process of identity development may emerge. At the same time she points to a nexus between getting “really sick” and social isolation:

RS: How does the work make you feel?

Caitlin: Well it takes your mind off your illness. It distracts you from the voices and um, yeah. (pause) the system is that if you get sick, they are very supportive and they will um like make allowances for you to have time off work and then go back to work and things like that.

RS: Do you feel like you are a different person at work?

Caitlin: Oh well, when you distract yourself from the voices then they're not so bad. But when you get really sick then you isolate yourself, don't do anything, that's when you get really sick.

Danielle was a highly capable respondent for whom employment is not just a distraction, and a venue for symbolic interaction, but also again a source of satisfaction:

RS: But you're holding down a job now?

Danielle: Yeah.

RS: Can you tell me a bit about what you're doing now?

Danielle: Yeah, I'm a admin officer. I just mostly do typing of reports, I make files up for patients and I answer incoming phone calls, what else do I do? Sometimes I do a lot of manual kind of work, I do a lot of that, like archiving files and taking files up to the medical record department when they need it

or when we need it, sometimes providing backup for the other departments on the phones, yeah, that's about it.

RS: How does the work make you feel?

Danielle: Yeah, satisfied.

Peter was perhaps not as capable as Danielle, but wished to work nevertheless:

Peter: Yeah, it will give me something to do plus it's, I'm empathetic in that area, so I can help people quite a bit with my knowledge of personal mental illness and that sort of thing. The only problem is my sleep problems but if I can get past that to a degree and do some part time work like with Richmond PRA or something like that then that'll be good.

Peter describes the reason for his desire to work. An interesting pattern amongst a number of respondents emerges here – a desire to work in the mental health sector. Sally, for example, has worked at the “Leisure Club”, a meeting space for people with mental illness. Typically respondents wanted to use their own experience to help people who may have experienced similar symptoms. In this sense they were able to turn the disruption of schizophrenia into a more positive experience. This desire also confirms Goffman’s thesis, explored further in the next chapter, that people with a stigmatised condition may seek out others with a similar condition. This process probably aided respondents to build a positive sense of identity:

RS: Would you like to help people?

Peter: Yeah, yeah, yeah definitely. Um, but ah, helping people appeals to me.

RS: Yeah, why?

Peter: Um, it gives me some satisfaction that I can be able to help someone and maybe prevent them from suiciding or something like that cause I've had many friends who have suicided.

Finally, Michael saw employment as a means of making money to re-decorate his apartment. In the sociological analysis made here, we must not lose sight of the prosaic:

RS: OK. Tell me about decorating your apartment?

Michael: I go shopping, pick up stuff, like I do fashion design, but I'm just doing home at the moment. Like homewares and stuff. So I'm just designing my home at the moment.

RS: Fantastic. And how do you afford it?

Michael: I work, I've got three jobs. I work at Croydon, I work at respite at Burwood, I also work at PRA in Figtree, Conference Centre at Olympic Park, um, where else do I get money from? Oh, that's all, and I've had a couple of private jobs.

I've only had, sorry, I've only had one private job cleaning, I didn't like it, that was last week, she was a bit too messy for me, I couldn't clean up after her.

Illness Management

Illness management may be thought of as activities that decrease the impact of symptoms upon a person's life. It may involve finding, buying and taking regular medication, meeting with psychiatrists, and compensating for permanent and fluctuating symptoms such as paranoia or discomfort in social situations. Illness management helps preserve well-developed post-diagnostic identities and helps prevent recurrent breakdown. In many cases respondents were helped in managing their illness by family members, case workers and psychiatrists. We have already encountered many cases of illness management (and mismanagement); be it a failure to take medication leading to relapse, or the maintenance of contact with psychiatrists. Such processes will form part of the concept of "identity work", suggested below in Chapter 9.

One of the important aspects of illness management is finding out information about the illness. With this information, the patient is able to begin constructing a narrative making sense of his or her condition. Information is also power. The fact that information generally involved a neurochemical explanation of the condition, necessitating neurochemical intervention, reinforces the power of psychopharmaceutical companies. Information can also empower the sufferer. It may be used as a tool for negotiation with the psychiatric apparatus, and can form the kernel of progressive illness narratives or the basis for a positive illness trajectory more generally. We have already seen Prescott describe his own efforts at research on the subject, on page 147, taking a proactive attitude.

Caitlin has learned vital social skills and, in particular, skills of symbolic interaction, also attesting to the help she has received to reach this state:

Caitlin: It's interesting because as I said years ago I used to be withdrawn all the time and not be able to speak and hold a conversation and things like that but now I can. (pause) I've learned that, you know, to express my feelings and how I am and how I'm doing and things like that. I've learned over the years to do that. Through a lot of help I've gotten and support I've gotten.

Danielle testifies to the importance of accepting the illness. As we have noted before, such insight is commonly seen by psychiatrists as a positive step towards wellness. Accepting the illness also entails accepting the psychiatric diagnosis and, usually, medication. Again we find the power of the psychopharmaceutical complex over the psychiatric process. Having an accurate self-concept would seem to be a firm basis to reform a sense of identity.

Danielle: Well, I just come to accept the illness and I think I'm generally at the moment much happier but that's only recently. Up until now I used to think many depressing things about myself, like about, I was hopeless or I wish I could die or you know, my father would say that I'm a coward if I did something to try and end my life or something like that or have that idea.

Ralph seemed adept at illness management, suggesting the diversity of illness experiences and patient responses. He spoke about putting strategies in place when things start to go wrong. Such strategies would seem highly important to maintain the interactions of everyday life. They also again speak to the significance of the sufferer acting as the agent within the confines of his or her illness. Such agency problematizes a top-down or one-way picture of power exercised over the person diagnosed with schizophrenia. It will also come to form an important part of the concept of "identity work" developed in Chapter 9. Finally, the emphasis on agency complicates a reductionist or deterministic account of the illness – one where a chemical process can be ameliorated only by medical intervention:

Ralph: So what I've gotta do is let that chemical process take its own accord and part of that strategy that I have is to do nothing, you know, have a nap, lie down with a bean bag over my eyes and a book under my head, you know in yoga nidre, doing nothing or do meditation and, you know, let that, not engage in that process but just let that process dissipate of its own accord and that's really worked for me.

He went on to define a practical life outlook including schizophrenia, one that suggests issues of the geography of schizophrenia – where a person diagnosed with the illness can best find a safe and not over-stimulating life:

Ralph: Part of moving down to Bega for the last couple of years is that increasingly I've found living in a big capital city too difficult and it wasn't conducive to my mental health, so I had to set about moving into a different space, um, I think, you know, staying off drugs and alcohol and um keeping out of hospital are the two priorities in my life. You know, and um I don't question them. You know, um, yeah.

Ralph's cooperation in determining his medication can be read as a form of illness management conducive to rebuilding a sense of identity. This again points to the concept of identity work developed in Chapter 9, as well as invoking the patient's potential agency and ability to negotiate with his or her psychiatrist:

Ralph: I even had a conversation with my psychiatrist about whether being living without medication in a psychotic state would be beneficial and I said to him "the thing that tires me out the most is that psychotic thinking", because I think I can solve it, whatever it is, I don't know, that, you know the world is an inherently messy place and you know when I'm psychotic and unwell I think I can make some understanding or some order of that world.

Another form of illness management emerged in the form of compensating for symptoms. Such compensation requires a fairly sophisticated degree of self-insight and, from a symbolic interactionist perspective, an ability to see the meaning of one's own gestures from the perspective of the other. To illustrate this we may look to the example of James how, knowing that he suffered paranoia, was pursuing a sexual interest whose apparent rebuffs he put down to his own paranoid perception. Interestingly, it is only with the intervention of friends – significant others – that James was able to "correct" his behaviour in light of his perceptions:

James: So there's one incidence where I fell in love with a woman at Church and she didn't like me but she didn't tell me straight out that she didn't like me she just kept doing all these behaviours to give me the message that she didn't like me and that I should back off. Now cause I knew that one of my symptoms is paranoia, I always attributed any negative behaviour on her part to um circumstances outside of her control that I didn't know about and I would just with being paranoid if I thought that she was trying to

deliberately behave like that so I just assumed that she wasn't trying to deliberately behave like that and so for years I kept trying to be friendly towards her while she was trying to be mean towards me. Well I didn't realise she was being mean towards me and finally it took a couple of different friends to say "actually, James, she is just not interested in you" and um even then like even then after I was pretty sure that she wasn't interested in me I specifically asked her and finally she told me straight out she wasn't but um, in actual fact her behaviour towards me was quite rude whereas I always assumed that she wasn't being rude, it was just me being paranoid.

It is very difficult to judge whether such an experience has a positive or negative effect on James's ongoing efforts to re-build a sense of identity. On the one hand, compensating for symptoms would seem to allow him to interact more naturally with people around him. On the other hand, as we have seen, he may over-compensate and progress to a state that was almost delusional. In any case, he is engaging in an active labour of stabilisation, working on himself to make fine judgments about reality testing and to overcome the limits of his experience of schizophrenia. This suggests a connection to Rose's portrayal of a governmentality that seeks to "reconceptualise themselves in terms of their own will to be healthy, to enjoy a maximised normality" (Rose, 1996b: 52). Of course, the questions must arise, what is "normal" and who is to judge "normality"? Certainly a picture of the functional self is given by symbolic interactionism – the ability to interact with others, the ability to understand the meaning implied by one's own gestures, and the ability to grasp the view of the generalised other – and may provide a yard-stick for normality. Regardless of the precise definition of normality, work must usually be done by the person diagnosed with schizophrenia to escape ontological crisis and biographical disruption. Such work may also happen during identity maintenance, as shown in the next chapter, and forms part of the concept of identity work suggested in Chapter 9.

Finally, Greg began receiving treatment in public hospitals but then sought out private health insurance:

Greg: Well, I was in a public hospital up until about, no. On and off, in and out of public hospital psych wards, ah, up until about 2009. And then I started

saving up for health insurance and paying for health insurance but you have to wait 12 months before you can claim and after that I started going to private hospitals.

Greg also saw a bulk-billing psychiatrist, although he was somewhat ambivalent about the psychiatrist:

RS: OK. Um, how do you feel about your psychiatrist?

Greg: I feel he's good but I would like to get a second opinion. Ah, he is a private psychiatrist but he bulk bills me because once upon a time when I used to see him when I was working these three jobs and everything I used to pay him up front and claim. Yeah, so he lets me bulk bill now.

Life Management and Goal Setting

Life management is a term used to refer to the management of day-to-day stresses; domestic and work-related. Effective life management allows the diagnosed person greater freedom to pursue social and work-related activities with others that can contribute to their rebuilding of a sense of identity. Challenges include finding work, finding and maintaining friendships, living happily with family members, managing finances, studying, exercising choice over life decisions and setting realistic life goals. In many cases, however, the diagnosed person may not be capable of comprehensive life management, or may set unrealistic goals. It becomes an interesting point whether the setting of unrealistic life goals may in fact still prove a positive aspect of life management, insofar as it provides a modicum of hope to people often trapped in a limiting situation.

Prescott talks about accepting schizophrenia, but still maintains a generally positive attitude. The point has been made already that a positive attitude seemed to be an important part of Prescott's process of rebuilding a sense of identity. There is no doubt that Prescott's successful response to

medication is also an important factor in his positive attitude. We may once again make the aside that phenomenology as it lies does not provide a strong account of how such phenomena as a positive attitude arise, influence recovery and rebuilding identity. As we will see in Chapter 9, the concepts of “reformation of body-in-the-world” and “ontological renovation” seek to address this flaw:

Prescott: I have to accept it and that's one of the things of the condition, that, I try and improve myself so I accept it but whilst I've got the ability to move forward, I've got the ability to apply myself to new things and try my very best to find a way of learning things considering I've problems remembering specific details.

Prescott's positivity was translated into a desire to reduce his reliance on social welfare:

Prescott: I mean but I was talking to the psychiatrist the other day because I'm on NewStart at the moment, um, I asked him to write me a letter saying that my condition was being managed cause I told Centrelink because I went on the DSP [Disability Support Pension] for a little while, so they knew that and I'd been working for the last five years, um, so, um, I asked the doctor to write me a letter saying that I had ... that my condition was being managed and that I'm able to work. So, that's what that was all about. So I explained, I had to tell them about the condition I had there.

Danielle describes an existence of relatively good life management, a description that chimed well with her self-presentation and coherence during the interview. Interestingly, life management involves a number of different behaviours, some as banal as presenting oneself positively or speaking clearly. Why is this interesting? It shows that the complexity of maintaining a positive outlook on life and positive symbolic interactions, among other factors, may come into play in life management:

RS: OK. Can you describe your life now?

Danielle: Yeah, its, I've got a good job, I'm good at my job, I usually have a good relationship with my family, usually, just reasonably good. I can look after myself reasonably well and look after my unit reasonably well. My hygiene is much better than when I was sick. I think that's about it really.

As we have seen above, Michael focused on self-presentation and fitting-out his apartment as a way to be pro-active and to distinguish himself from other people with schizophrenia. Interestingly, in the very act of distinguishing himself, he is re-affirming the stigma that accompanies schizophrenia:

Michael: I keep myself immaculate ... a lot of schizophrenic people are like very messy and they are very untidy but I'm not like that, I'm very immaculate. I think I've only got slightly schizophrenia, I don't think I've got it totally, you know. Full blown ... cause I still can picture whether it's real or not.

RS: OK. Tell me about decorating your apartment.

Michael: I go shopping, pick up stuff, like I do fashion design, but I'm just doing home at the moment. Like homewares and stuff. So I'm just designing my home at the moment.

Nathan describes a reliance on a smartphone to “run his life’. This may suggest an interesting side-issue to research – the reliance of the mentally ill on technology and how technology can be used to improve the life quality of sufferers.

Nathan: I'd have to do like chores, looking after my birds, doing the activities that I have to do week by week, planning my weekly activities, my meetings with case workers, my meetings with any courses that I'm doing, all of that, it started to change and it started to become like a need to um to become more organised, but without these electronic smartphones and things like that, I would be in a very disorganised disorderly way. That is my secretary, that is my reminder service, it basically runs my life, my smartphone is my life.

Goal setting is an important element in life management. It shows a confidence in life and a forward-looking perspective, as well as a relatively stable identity. However, a number of respondents seemed to have set personal goals that would be hard to achieve, particularly in a competitive, deregulated economy and a social world that seriously stigmatises the condition of people diagnosed with schizophrenia. In these cases it is difficult to judge whether the goal setting helped or hindered the re-establishment of a sense of self: whilst such goals may motivate the respondent, their ultimate failure to reach the goal may lead to negative self-esteem and frustration.

Prescott talks about the goals he was setting at the time he was diagnosed, and how having schizophrenia challenged those goals. We see here an acceptance that his pre-illness goals may be much harder to reach; a certain pragmatic realism in attitude that would seem to bode well for the process of rebuilding a sense of identity. It is also significant that his goals include having serious relationships – significant because it again affirms the need for significant others in symbolic interactions:

Prescott: They were to finish university, they were looking after myself with some sort of job and some sort of, you know, family life, girlfriend etc, that sort of thing. So those sort of three aspects of it and the way I understood mental illness was that this was going to be harder for me to get to that stage that other people sort of take as a general step in their life.

RS: Did you feel that it was fair?

Prescott: No, I didn't think it was fair. I was very unlucky to have caught myself with this situation, (pause), so I was, um, thought it was very unfair.

RS: OK and what did you do with those feelings of unfairness?

Prescott: OK, um, what did I do with the feelings ... well I sort of thought, you know, like I put that into trying to, you know, start on a path that was going to get to those goals. Those goals of ideas that have completed schooling, having a job and being a responsible family guy as well as being a supportive person to, like, relationships outside of the home in the social situation, in society.

Typically life goals expressed by respondents involved living a happy life, working and having a family. Nathan, for example, outlined the classic position (despite heavy medication that seemed to have precluded him from taking part in many life activities). One may only speculate on the power of hope – the significance of hoping for a brighter day. Such hope may help combat the thoughts that may lead a sufferer down a darker path. Alternatively, to draw on analysis made in the previous chapter, hope is an emotion that would affect a sufferer's symbolic interactions yet hope, as an emotion, is not well-theorised in traditional symbolic interactionism:

RS: OK. Um, do you have any long term goals?

Nathan: Um, my long term goals are to live a happy life, to have a good relationship with the supreme soul of the universe, to have kids, a couple of kids and have a marriage, to become a grandparent and to die.

Peter had somewhat less ambitious, but probably more achievable, life goals. Peter seems to have let go of more difficult or demanding dreams, having accepted his situation:

RS: So what are your goals for 10 years?
Peter: 10 years, um, to have been working part time in the mental health area to have saved a reasonable amount of money, so that I can have plenty of money to keep the car on the road and all that sort of thing, to feel that I have achieved a fair bit, maybe to complete some more study and that sort of thing.

Nathan emphasised the difficulties he faced in achieving life goals, again struggling with acceptance of his situation:

Nathan: I felt as if like, if there was a race and that race was to achieve in your job that I was 10 metres behind cause I was on these inhibitors and so I felt that I was severely disabled, because of what I had to do.

He describes far more restricted goals than some respondents. The emphasis he puts on the PHaMs (Personal Helpers and Mentors program) below is significant because it shows the degree to which rebuilding a sense of identity through successful life management may be abetted by a supportive social environment; the social complements the neurochemical intervention. The PHaMs program may also be described as a result of the deinstitutionalisation process, focusing on providing care in the community. It also accords with Rose's description of "de-statising" public services; the PHaMs mentor may rely on government funds, but the support appears to be provided as a private service. As such, we may also understand programs such as PHaMs as necessary elements of care in a deinstitutionalised environment. The precise nature of this care – the fact that it appears dispersed and capillary rather than centralised in one location – will also inform our analysis of power exercised over people with severe mental illness in a deinstitutionalised environment:

Nathan: I didn't like that the schizophrenia actually had control over me and that when I ceased using drugs suddenly I started to see the world differently, I started to, the clarity started to come back a bit more ... So I, I, the goal, my goals took maybe 12 years before I came up with the PHaMs program [a Personal Help and Mentor program] and they helped me to work on a compass to work out to how do I get to my goal, when's that to be. I mean before I had schizophrenia I thought I was gonna have the picket fence, the job, maybe an engineer, um, a family, at least 2 children, something like that

and, you know, that I would be a grandfather and all that sort of thing. Um, now, it's sort of my goal now is to just meditate and to um ... be patient and to just to have the main goal to live happily ever after and to cease using all the drugs, illicit drugs, that is.

Likewise, Ralph emphasised the change of life goals forced upon him by his illness, and the impact this has had on his life:

Ralph: I've kind of let go of a lot, you know, even my work life, um, my ambitions in life have to be um [pause] whatever I do in my life, whether it's in my daily life or, you know, the aspirations I have for my 5 years or 10 years down the track, my illness also has to be considered.

However, Ralph also seems to have come to terms with his change of life goals:

Ralph: You know, have a bit of compassion for myself, stop taking the whip out and whippin myself, for things that I haven't achieved and I haven't done because I have a mental health condition and I think that compassion, if I can be compassionate for myself and understanding of my condition if I then transfer that compassion or understanding onto others the world's gonna be a better place, you know. Maybe it won't save, you know, it won't bring world peace and harmony, but you know, at least it's going in the orderly direction, at least it's going in a good direction.

Arthur seemed to be living a life without goals, contemplating death, giving his interview a certain melancholy. A certain grim realism may present yet another strategy in rebuilding and maintaining a viable self; even if that self is without hope:

Arthur: Oh well, I'm just stuck with myself, I guess I'm faced with the reality that I'll probably be dead within five years, you know, so I guess anything is better than that I guess, I mean death's a pretty final thing as far as anyone knows anyway. So, you know, I guess anything seems better than death, I guess, you know. So what can you do, you know.

It was unclear in the interview why Arthur, at age 62, thought he would be dead in 5 years.

Finally, Michael: revealed in his interview that a life goal was to make money. This was a singular response amongst interviewees; an interesting insight into one path towards rebuilding a sense of self.

RS: OK. What makes you happy?

M: *Um. Fashion, my home, my family. My job, money. I love money, money makes me happy.*

Religion

One theme that emerged strongly amongst a very small number of respondents was the importance of religion in rebuilding a sense of identity. Participating in religion – through religious services, providing a clear symbolic system or world-view, and, perhaps more importantly, religious group activities – could help the sufferer come to terms with his or her condition and, through the social activity important to symbolic interactionism, re-build his or her sense of identity.

Although this would seem to be an important route to rebuilding a sense of identity, only one respondent – James – talked at length about the role of religion in his life. However, before examining James's interview it is worth noting the generally positive view of religion held by Sally:

RS: *Do you have faith or religion?*
Sally: *Have faith?*
RS: *Do you believe in God?*
Sally: *Um, yeah.*
RS: *How do you reconcile, um, the fact that you're sick and the fact that there's a god?*
Sally: *Um, I'm pretty happy, um, I go to church every week and um have no problem believing in God, you know, I don't have the symptoms of schizophrenia at the moment so, yeah. [pause] I think my religion helps me.*
RS: *How does it help you?*
Sally: *Um, like um, I feel comfortable. Yeah. Good things happen when I go to church and good feelings.*

Similarly Greg, who had converted to Islam relatively recently, spoke fairly positively of religion:

RS: *OK. And what does religion provide you with?*
Greg: *Little bit of hope and um, it's so hard when I'm feeling down to have faith. Yeah.*

Where Sally and Greg experience happiness of a certain extent from going to Church, James has a significant amount of his life tied up with the institution. Indeed, James emphasises the social role Church has for him; one where he could engage in symbolic interaction with a group of people and one where it was generally known and accepted that he had schizophrenia. Indeed, Church seems to be a central feature of James's life. Further, religion can provide James with a system of explanation in which his illness may be seen as part of "God's plan", or otherwise having specific meaning. The brief mention of Facebook returns to the side-theme of people using technology to return from schizophrenia:

RS: How many friends do you have?

James: I've got heaps. Um ... I'm Christian, I go to church and I've got a lot of friends from Church. There's a Monday afternoon group of people that I meet with on a regular basis and there's a Tuesday evening group of people that I meet with on a regular basis and mostly those two groups are the same people but not completely. Um, so there's the friends from the Monday afternoon group and the Tuesday night group that I see every week or twice a week. Um, then I've got various other friends in the Church. I play bass in the Church band and so I see the people who I play in the band with more often than other people in the Church because I'm with the same group of people each time so there's these friends, um, then like with this Tuesday night group, Tuesday evening group, I've always been in a Tuesday evening group since I've been at the Church, but for one reason or another I've either changed groups or the group I've been in has disbanded so there's been a couple of different groups I've been in so I've been friends with all the people from the groups I've been in previous to the one I've been in now and am still friends with those people if they're still at the Church or even I'm Facebook friends with some of the people who left the Church and I don't see very often. Um, then there's just friends that I just know from being at the Church for a long time so I see the same people and I've become friends with, particularly catching up with people on different um Christian ... on the Church camps or other opportunity or conferences...

James goes on to emphasise the change in values that religious life has brought him – he is able to pursue compassion and non-earthly pursuits regardless of his schizophrenia; this provides a basis for rebuilding a sense of identity. He even claims to want to be like Jesus. In the opinion of the interviewer, this was a meaningful life goal rather than a delusion. An issue that has not been broached so far is that of the role model. It seems in a stigmatising society a person with the stigmatised condition could benefit from positive role models:

- RS: *[W]hat helps you believe in yourself?*
- James: *[pause] um Well I think my Christian faith because um I don't ... my highest values are not the things that the world values and so even if I'm not able to do things the way that society thinks it's appropriate it doesn't matter, because the things I can't do are not the things I think are really valuable because of my Christian faith, so like for example I think my character is more important than my ability to socialise with really good etiquette for example.*
- RS: *How would you describe your character?*
- James: *Well, um, I ... it's ... I think I've got a good character but I am seeking to become like Jesus and I think that's happening over time.*
- RS: *How is Jesus? What about Jesus is it that you want to become?*
- James: *Oh, there's lots of things, I mean, um, Jesus was motivated by love, ah, he was completely forgiving, um, he never did anything out of revenge or seeking to hurt someone or put them down, um [pause], he was motivated to help people and make the world a better place.*

Analysis and Emergent Themes

There are a number of emergent themes and significant lines of analysis that develop from this chapter. It is worth noting that some of the emergent themes echo those made in the last chapter. In particular, the emphasis on agency and negotiation with the psychiatric apparatus emerges strongly. We see a number of interviewees negotiating their medication, or resisting aspects of institutionalised or stigmatised identity. We also find a rejection of the one-way, top-down exercise of power. Again, the negotiated and consensual aspects of interaction with the psychiatric apparatus emerge, and indicate the need to conceptualise new forms of power in an era characterised by deinstitutionalisation and psychopharmacology. With agency and negotiation also comes a blurring of coercion and consent in some cases. The problem of symbolic interactionism dealing with emotions and embodied states also arises. The scale of the process of rebuilding a sense of identity stands to be as significant and intense as the disruption that came with the illness. Finally, we find that phenomenology, whilst accounting well for identity breakdown in schizophrenia, does not provide an adequate conceptualisation of rebuilding identity. Beyond these themes, however, the chapter gives rise to a number of important, distinct lines of analysis.

The first line of analysis relates to the near-ubiquity of medication as an intervention in the illness trajectory of people diagnosed with schizophrenia. Medication is simply seen as the first and most important means to dampen schizophrenic symptoms (American Psychiatric Association, 1997; Williams et al., 1999; Lehman et al., 2004, Sadock and Sadock, 2007; Busch et al., 2009; Hope and Keks, 2015). The importance of medication is reinforced throughout this Chapter; almost all interviewees could discuss their medical regime. Some even had enough insight into their condition and familiarity with the effects of medication that they could negotiate their medication with their psychiatrists. The ubiquity of medication is important to themes both of rebuilding a sense of identity and the power exercised over the person diagnosed with schizophrenia. In terms of identity, the emphasis on medication tends to imply that the person's mental state could not only be affected by medication but was constituted by the kind of biochemical phenomena that medication could influence. Put differently, they experienced themselves as medical identities – as a person who takes medication. More fundamentally, they understood their identity as the result of biochemical processes in the brain amenable to medication. In this sense, a “neurochemical self” had arrived. In terms of power, the ubiquity of medication implies the power of the psychopharmaceutical complex to create and define treatment of schizophrenia. The complex has not only colonised the practice of psychiatry in relation to people diagnosed with schizophrenia, it has reached into the very identity of the sufferer.

The second line of analysis relates to the uses of symbolic interactionism. Symbolic interactionism proves an adaptable and useful tool with which to analyse processes of rebuilding a sense of identity, and the activities that aid and abet it. In particular, the symbolic interactionist model of “self as process” is vital to our understanding of rebuilding identity itself as a process. Symbolic interactionism also provides something of a model towards which the process of rebuilding identity can strive – a social self that can interact with others, that understands the meaning of its own

interaction, and can take on the viewpoint or attitude of the general other. The focus on the inevitably social nature of the self is supported by the various social activities that contribute to processes of rebuilding identity and that subjects describe in their interviews; activities such as interaction with family and friends, visits by mental health workers, and time spent at such mental health support organisations as the Leisure Centre. The idea that different parts of the self may emerge in different circumstances is also strong; in rebuilding the self, the active patient usually interacts comfortably with a range of people in different circumstances. As a reversal of this concept, some of the more isolated interviewees would not seem to have the chance to project different aspects of identity in different situations, and this may threaten processes of rebuilding a sense of identity. The focus on meaning as the product of interaction is also useful as it allows us to analyse the meaningful expressions of people diagnosed with schizophrenia – not only the interview transcripts themselves, but also the illness narratives sufferers may create (and which are considered further below).

A third line of analysis, developing from the first, is the sheer significance interaction played in the process of rebuilding a sense of identity. The scope for such interaction was wide. It included the interactions noted above – interactions with family and friends, with employers, with psychiatrists and mental health workers, and with segments of the community in mental health support organisations as the Leisure Centre, or the church. This line of analysis is significant because it suggests that some of the key areas affected by certain schizophrenic symptoms – that of reading emotional cues, projecting affect, and maintaining meaningful interaction – are in fact closely tied to recovery from schizophrenia. The illness thus undermines the self, even when the sufferer may wish to recover. Such an insight reinforces the point made in the previous chapter, that schizophrenia can prove a vital disruption to the self.

Just as interaction seems to have broad significance for rebuilding a sense of identity, so too do practical measures that may not appear significant from a strictly medical perspective. By “practical measures” this thesis refers to such behaviours as sourcing medication, travelling to see psychiatrists, working for money, goal setting, living happily with family members, managing finances and so forth. Such activities would not seem to have a direct medical or biochemical impact upon schizophrenia. However, the data presented here tends to suggest that these activities are significant to the process of rebuilding a sense of identity. We may take the example of working as a practical activity. Work provides a venue for social interaction and a distraction from ongoing symptoms. It offers a sense of purpose and achievement. And, of course, it provides money for the living of a more comfortable life. We can thus perhaps make the argument that sociological factors are perhaps sometimes under-developed in medical analyses of recovery from schizophrenia, although employment is seen as a positive goal for many psychiatrists. The response to this situation should be to recognise such sociological factors. In particular, we must use a more rounded picture of the person diagnosed with schizophrenia. Whilst his or her symptoms may prove the reason for his or her diagnosis and treatment, and constitute the nature of disruption of his or her experience, he or she nevertheless must also go through the practical activities of a well person to fully inhabit and express their identity. We may also make the observation that partaking in these practical measures also takes the sufferer out of the sphere of influence of the psychiatric profession. Although they may still need help to engage in these activities, and such help may come from mental health workers, they nevertheless are aiming towards living a life of independence.

Just as interaction and practical management of day-to-day issues prove important, so too is the use of specific forms of language. This thesis identifies three important uses of language by people diagnosed with schizophrenia, and these uses are analysed in depth in Chapter 9. However, we may make some preliminary analysis of these uses of language. The first such use lies in illness narratives told by sufferers. It would seem such narratives help the person diagnosed with schizophrenia make

sense of their illness experience, an often chaotic time. In some sense they heal the “temporal breach” caused by biographical disruption, or even biographical crisis. The second use lies in the adoption of psychiatric discourse in describing the nature of the sufferer’s experience. Using this language clearly implies the reach and influence of the psychiatric profession; from a Foucauldian perspective, subjects have adopted the discourse of the disciplinary institution, and involved themselves in a complex web of power/knowledge. Such use also may play two important, but perhaps slightly contradictory roles. On the one hand, use of psychiatric terminology, along with knowledge of medication, may help a person diagnosed with schizophrenia to make sense of his or her illness trajectory and experience. On the other hand, the very formality of psychiatric discourse may help the sufferer objectify their illness, or create a formal distance between the psychiatric reification of illness and their specific, various personal experiences. Finally, we find that some interviewees describe themselves as “consumers”. This language use again has multiple significances. On the one hand, the term itself does not speak of illness, stigma or disability – it escapes psychiatric discourse and allows the sufferer to describe him or herself in less stigmatised terms. On the other hand, the term tends to imply that the person diagnosed with schizophrenia is “consuming” a mental health “product”. The term thus suggests that the sufferer seeking medical help is actually participating in a market for mental health goods. This, in turn, serves to help justify the power and influence of the psychopharmaceutical complex. This complex has not only colonised psychiatry, it has infiltrated the consumers’ rights movement.

Moving on from language use – a personal and expressive aspect of the illness experience – this chapter also addresses issues of power and social structure. The first issue to be dealt with in this context is deinstitutionalisation. It was clear that almost all interviewees had in fact spent at least some time in a clinic or hospital, but had ended up residing with family or, in some cases, living alone. Whilst it is true that many interviewees were visited fairly frequently by mental health workers, they still spent an inordinate amount of time without interaction; without socialisation.

Such a situation speaks to the pervasive isolation felt by many interviewees. The deinstitutionalisation of the mental health sector must be understood as a vital historical process leading to this situation. In many cases isolation was expounded by family members who did not understand, and sometimes did not accept, their relative's illness. One must assume that these relatives had not been provided with the resources or information necessary to support a family member diagnosed with schizophrenia. This situation of deinstitutionalised care has important implications for the discussion of power in the thesis. It suggests that the power of the psychiatric apparatus is no longer exercised within one or two spaces – the psychiatrist's office and the asylum – but is more dispersed, capillary. It suggests that perhaps psychiatric power is being delegated outwards from primary players in the psychiatric apparatus. It also suggests, more broadly, that society itself still stigmatises schizophrenia to a significant degree, and has not yet made a real commitment to effective in-community care. Indeed, we may look to the statistic related at the beginning of this thesis – that something like one in one hundred people will develop schizophrenia – and wonder why so little is being done about a problem so vast.

The chapter also implies other issues of social structure. The most obvious issue lies in the recognition of the power and influence of the psychiatric apparatus. We have already seen that diagnosis – a key interaction with the apparatus – may have important impacts upon the identity of the person diagnosed with schizophrenia. The fact that interviewees continued to see their psychiatrists or other representatives of the psychiatric apparatus regularly again attests to the power of this institution. However, as we have seen, this power may be dispersed in a deinstitutionalised era. Whilst interviewees still generally spent some time in clinics or wards, and experienced some of the identity-shaping and power effects of such institutions, they had all been released into the community at the time of interviewing. For many the only contact with the psychiatric apparatus (for some, the social world) was constituted by visits from mental health workers. In such a context we must reassess traditional pictures of power exercised by psychiatry;

the social control thesis and critique of asylums and disciplinary institutions must give way to concepts of newer forms of power. These are explored towards the end of Chapter 9.

We have noted the gendered division of labour James relied upon in order to deal with some of the more practical aspects of daily living. One may assume, in a patriarchal society, that such division of labour probably still exists for some people diagnosed with schizophrenia living with family or partners. The gendered nature of the experience of schizoid illness would seem to provide several interesting avenues for future research. More broadly, the family unit seemed to play an important role in the process of rebuilding a sense of identity for many interviewees. This was evidenced by the fact that interviewees such as Prescott, who appeared to be living with their illness more successfully, had strong relationships with their family. Likewise, the experience of family breakdown in emotional or physical violence often seemed to intensify the disruption caused by the illness and had a negative impact on the process of rebuilding identity. Along similar lines, it has been argued that a surfeit of “expressed emotion” in the family of the person with schizophrenia can lead to less positive recovery outcomes (Brown et al., 1972; Leff, 1995; Lopez et al., 2009).

The importance of work towards the process of rebuilding a sense of identity also merits analysis. We have noted that work often provides a venue for social interaction, a distraction from ongoing symptoms and sense of purpose and achievement for people diagnosed with schizophrenia. In terms of identity, we may say in an economy with advanced division of labour and where work is seen to be vital towards general identity formation, it should come as no surprise that successfully holding down a job, or jobs, played an important role in the process of rebuilding identity for people diagnosed with schizophrenia. We may also ask the question of political economics whether there is room for work for people with mental illness in a fiercely competitive, deregulated economy? Certainly the data suggests that when sufferers did find work, it was generally menial in nature. This may of course be dictated to some extent by the fact that the illness schizophrenia can decrease

cognitive ability. On the other hand, issues of stigma must also play some part in the difficulty people with such a stigmatised condition experience when seeking more challenging work.

In terms of social structure, we may also note the theme that many interviewees had spent time with organisations geared towards support of people with mental illness. The fact that at least two interviewees had visited the Leisure Centre – an organisation for mental health support and entertainment – is significant. It points to and reaffirms the observation made by Goffman that people with stigmatised identities will often seek out people with similar stigmatic conditions. It also makes sense that people suffering the kind of isolation described above would seek out social interaction; even if it were compromised by the fact that it is not with the general community but with a small segment sharing a lived experience of mental illness. Visiting such centres may also be read as an attempt by the sufferer of schizophrenia to move in a social world beyond the psychiatric apparatus; a world characterised not by stigma, or the stern rule of the clinic, but by mutual respect and a non-judgmental atmosphere. It may be interesting to note at this point that at least one interviewee, James, seemed to find such a non-judgmental community in his church.

The final theme to emerge from the data of this chapter is the importance of hope and despair. Hope certainly seemed to be an important part of the process of rebuilding a sense of identity for many interviewees. Whilst it is true that some interviewees adopted a grimly realistic approach to their own lives and goal setting, other interviewees typically hoped to one day lead a “normal” life, to work, to marry, to have a family. Hope was expressed in the personal goals set by many interviewees, even (or especially) if those goals seemed unlikely to be achieved. Hope for a better day seemed to offer some motivation to people, positivity at the prospect of something greater. Such hope may be religious; a hope for salvation. Of course, the flip side of hope was despair, and at least a few interviewees spoke of moments of darkness. It is in such an emotional context that we may breach the issue of suicide. It is documented that people with schizophrenia have a far higher

rate of attempting suicide than the societal average. Suicide attempts, the ultimate negation of all identity, of rebuilding and maintain a sense of identity, appeared as dark chapters in many of the illness narratives spoken by interviewees. Indeed, the stories of those diagnosed with schizophrenia who successfully committed suicide are generally shrouded by sadness and an impenetrable darkness; these are stories that are not being told and, perhaps, can never be.

CHAPTER 8

Results: Maintaining Identity

Schizophrenia is a highly stigmatised condition and, other than processes discussed in the previous chapter, people diagnosed with schizophrenia must often go to great lengths to protect a stigmatised identity. To this end, this chapter draws particularly on the account of identity management given by Goffman (1963) in *Stigma: Notes on the Management of Spoiled Identity*. The chapter focuses on such processes as dividing friends into those who “know” and “don’t know”, as well as “passing” as normal in social situations and “concealing” stigma symbols such as paranoia or weak emotional perception. In many cases, passing and concealing involve respondents compensating or actively dissembling their condition. In some cases social isolation is such that respondents do not even have the opportunity to seek to pass or conceal.

Passing, Compensating and Isolation

Typically respondents would tell family of their condition, but generally not friends. This confirms Goffman’s observation that stigmatised people will often divide their social world into a small group who knows and a large group who do not. Caitlin, for example, would not tell her few friends of her condition. Caitlin is also interesting, and again confirms Goffman’s analysis, in that she would only readily disclose her condition to another person in similar circumstances.

Caitlin: Well, unless people have got a similar illness, you don’t tell them you got an illness. You don’t mention it. I don’t. Um, if I had a friend who didn’t have a mental illness I would not tell that friend that I’ve got a mental illness. That’s the way I am. Yeah, so. Yeah.

In other situations she would seek to pass as “normal”. However, Caitlin led a very solitary life and would not have had frequent opportunities to pass. Caitlin also confirms Goffman’s analysis in the

sense that she has sought out a group of people with similar stigma. Such groups would offer the opportunity to interact with other people without needing to pass or conceal stigma symbols, whilst participating in “everyday” activities they may otherwise avoid:

Caitlin: I used to go to a place which is called the Leisure Club which is a house for people with mental illness go there and spend the day. Have you heard of places like that?... Well you go there and you have lunch there, you buy your lunch, you do arts and crafts, you go on outings, ten pin bowling or you go to the beach.

Furthermore, Caitlin confirms Goffman’s insight that people with stigma may withdraw from social interaction, often losing friends; particularly ones who also suffered schizophrenia. Such withdrawal may occur as a foreseeable process in people whose ability to interact is compromised by their illness and its symptoms:

RS: Do you have friends?
Caitlin: No, friends, I’ve just lost touch with. I used to go out with her and everything but not anymore, she got sick, she’s got schizophrenia and we’ve never got back together again as friends.

Greg also visited a drop-in centre for a time, but ultimately rejected it for the reason that it was “full of sick people”. This action is contrary to Goffman’s insight that stigmatised people may seek to spend time with people sharing a stigmatised identity. It may also show a resistance to stigma; in particular, a resistance to an externally imposed identity:

RS: And are there any places that you go to spend time with other people?
Greg: Like a drop in centre?
RS: Yes.
Greg: Um, I used to but I don’t want to go anymore.
RS: Why not?
Greg: They’re justpause..... I don’t know, full of sick people. I wanna try to stay away. Yeah.

Arthur is very conscious of how he is perceived, arguing that he is not perceived as ill by people who do not know him, but accepting that people who know him well can probably identify something is “different”. What does this say about stigma? At one level it represents an internalisation of an external point of view; we may thus make a link to symbolic interactionism’s focus on internalisation

of the perspective of the other. It may also show how serious stigma instigates the futility a person diagnosed with schizophrenia may experience at the scale of the task of illness management. Arthur is not confident in his ability to pass or conceal stigma symbols. This, amongst other factors, leads him to live a solitary life where his sense of self has little opportunity to be maintained. This is perhaps a common experience amongst people with severe schizophrenia, bringing, as it does, flattened affect, difficulties in maintaining conversation and weak emotional perception, not-to-mention side-effects of medication that may include tremors, excess saliva production and weight gain:

Arthur: I think increasingly over the years, people have come to see me as something pretty sub-normal, generally, you know, but it varies from where I go, I suppose, you know, if I'm just walking down the street or shopping centre, I don't suppose people see me much different as someone else, but the neighbours in the street, it's quite clear that they see me as something unusual, you know, so, you know, and people who see me on a regular basis obviously see me as something unusual.

Arthur is clearly highly conscious of the views of neighbours, the social other, who reinforce his sense of his own stigma; that is to say, his hyper-awareness reinforces self-stigma.

We have seen that some respondents use the term “consumer” to describe themselves. The term may also be understood as an attempt to escape the stigma that accompanies the terms “schizophrenia” and “schizophrenic”. Whilst this is a strong example of stigma management, it also enjoins the personal interaction to larger, “macro” features of society. We have already noted the connection between the term consumer and the creation of a consumer marketplace for medicine, implying the power of the psychopharmaceutical complex. The use of such a term to deflect stigma also shows that people may internalise the stigmatic view of the other, whilst also constituting a winding-back of control over one’s self-description:

PM ...it's a bit of strange situation, all the consumers together like that, because there is obviously that locked area that they don't let you in and you got to stay inside the locked area they keep you in and you have to relate to people. So, you can't just run away.

RS: You called them consumers?

Prescott: Yeah, that was what I thought as being the most recent description of somebody with my condition. A mental health consumer.

Peter also describes his social isolation, even admitting that such isolation may in fact worsen psychotic symptoms, rather than (or as well as) providing a space where the person with schizophrenia does not need to pass or conceal. This certainly emphasises the role of social interaction as a core element of identity maintenance:

Peter: Um, no I've been living on my own for many many many years, um, you know, extreme amounts of time, I've been living on my own and that sort of brings isolation in and the schizophrenia tends to play up with me living on my own and I tend to think people are out to get me and all that sort of thing.

Peter also admits the severe stigma of schizophrenia; perhaps the driving factor behind his isolation. He does not – indeed, perhaps cannot – seek to challenge the structural features of society that create this stigma, although he does register a sense of the unfairness or hurtfulness of such stigma:

Peter: Oh, people, a lot of people out there who are so called normal, um, those people tend to have a misinterpretation of people with mental illness. They seem to think we are nutcases or fruitcakes or whatever ...

When not isolated, it seems that Peter seeks to compensate for symptoms he may be experiencing. More specifically, he tries to be aware of his own tendency to paranoia. Such compensation is a conscious, ongoing work of stigma management, a form of concealment fitting comfortably into Goffman's analysis. We may also draw a connection here to Rose's argument that in neoliberal states a system of governmentality exists that seeks processes for people to "maximise normality":

Peter: Compensate? Um, compensate, um, yeah well always trying to, trying to put it in perspective all the time, so, I'm always trying to put it in perspective, so um, compensate, yeah. I guess I am compensating in that I sort of try to ignore when it seems as though people are talking about me and that sort of thing, I try to ignore it and say it's my illness.

Peter's compensation involves insight into his condition. We have seen the significance placed upon insight by the psychiatric apparatus as a key step in recovery. It would seem, judging by the insight into their illness held by the majority of respondents, that insight is also a primary step in preserving

some sense of identity, although it may have been the sufferers with more insight that self-selected as interview subjects, and this may affect the direction of the data. This emphasis on insight would also certainly chime with the importance many psychiatrists place on insight as vital to the healing process of people with schizophrenia. Insight into one's self, and the perception of one's self by others, would also seem to be pre-conditions of stigma management:

RS: What does the insight feel like?
Peter: It feels good, because at least I know that getting strange ideas, ah and uh people talk about me, at least I can look at it and say that they're obviously, they're not saying that um, they're saying something else and um interpreting it differently.

Like Caitlin earlier, Danielle makes a point of concealing her illness, confirming Goffman's analysis. Danielle differs from Caitlin, however, in that she works regularly and did not report experiencing ongoing symptoms, whereas Caitlin experienced hearing negative voices. This may again point to the significance of social interaction as a basis for identity maintenance. Alternatively, it may reveal that the extent to which one may manage stigma is affected by the intensity of schizophrenia symptoms. She also does not seem as concerned whether people knew she "has something":

Danielle: I don't tell anyone really, that I've got schizophrenia. I just assume that people at work know that I have something. I think not everyone knows but some people know that I have it. Yeah, I don't really tell anyone that I have schizophrenia.

Greg also compensates for his illness, to the point of admitting he was concentrating during the interview. Again, the strength of symptoms affects the sufferer's ability to manage his or her interactions and maintain identity:

RS: When you have, when you meet people, do you have to compensate for what's going on in your head?
Greg: How? Concentrate more?
RS: Concentrate more.
Greg: Yes, yes.
RS: So what do you do when you concentrate more?
Greg: Just really listen intently and focus, try to focus.
RS: Yeah. Are you doing that now?

Greg: Most of the interview.

The importance of passing is made clear by Michael, who focuses on self-delivery and self-presentation. Indeed, careful self-presentation by Michael seemed to be his primary strategy, not only at passing, but to maintain a sense of self-worth:

Michael: I'm just well aware of myself, I'm just a nice person.

RS: OK.

Michael: That's what I think, I deliver myself well, I dress well, I speak well.

Passing is essentially a form of self-presentation. An interesting insight into passing and self-presentation is made by James, who discusses the importance of etiquette and learned self-presentation – also a form of symbolic interaction. We may at this point expand on Goffman's account to emphasise the need of sufferers to learn new forms of behaviour management in light of the unexpected disruption of schizophrenia:

James: Just ... every now and then, it didn't actually happen very often, it just, every now and then I would be aware that I wasn't within the social norm and I'd feel like I was a, yeah, a bit strange

RS: Was there anything that reinforced that feeling?

James: Not being familiar with etiquette, like, um, my parents didn't bring me up with all the things that a lot of people in our society regard as etiquette, so when I would stumble in these areas, it would make me feel a bit strange as well. Even though that didn't actually have anything to do with the schizophrenia. But I would still feel a bit strange.

James echoes earlier themes in that he would guard against telling too many people:

James: Um [pause] I've never had to hide it, um, there's people that I haven't told, um, there's people who I've known who I've thought made more superficial judgements about people that I just chose not to tell. Um, I never felt like I had to hide it but I felt like it was a good idea in a number of cases.

We have seen in the previous chapter the effects of over-compensation by James, so his story will not be re-told here. However, Robert gives us a detailed insight (to use a term already emphasised) into his condition and the forms of compensation he engages in. His compensation seems to be both

external and internal; he recognises the significance of behaviours such as yoga, meditation and sleep to a “healthier” sense of self. His story also attests to the role of others in supporting and directing stigma management behaviours. Robert certainly appeared at the time of interview to have a relatively strong sense of identity.

Robert: I think part of um compensating for my illness is knowing what’s good for me, yoga, meditation, good food, good sleep um supportive people in my life who are going to be honest with me, um and who aren’t going to condone bad behaviour by me when they see it, not that I do it all the time, but you know, sometimes I can say things or do things because I’m not thinking properly and I’m not considering the outcomes for other people, um, yeah and who aren’t necessarily gonna be overly critical.

RS: So when you say talking about considering outcomes, are you kind of compensating for things that you might do wrong?

Robert: Yeah, yeah, I’d certainly be mindful that, you know, if I think, if I consider that people may be as sensitive as me, I think that’s a good starting place, um, you know, if I give them due considerations so that, you know, I’m on time, I’m polite, I’m courteous,

Robert confirms the impact of the stigma of schizophrenia, recognising its historical and social embeddedness:

Robert: I would be um in blissful ignorance if I didn’t also acknowledge the effect that it’s had on my family and my friends and my social group and the stigma - you know mental health in the last 10 years has come a long way but, you know, 25 years ago, there was a lot of stigma. Still is around um mental health and schizophrenia, crikey, that’s a bit red-hot.

Robert clearly knew the stigma of terms like “schizophrenia” or, in the following excerpt, “sufferers”.

We may also draw attention to the fact that he describes himself as “psychotic on occasion” and gets a better response than revealing full-blown schizophrenia. This is clearly a sophisticated form of self presentation and another form of passing as more “normal” than he would otherwise be judged.

This will also prove important in an analysis of the significance of language use in and around schizophrenia, by sufferers and others:

Robert: I went once to the Schizophrenia Fellowship meeting and it really surprised me and they said, they were at the registration table and they said um, you know, are you a doctor, are you a nurse, or where do you fit so that we can charge you the right amount and I said “oh I’ve just got schizophrenia” and they said “you are a sufferer ...”. You know, and I thought, OK, I suffer from schizophrenia and that’s OK. You know it’s, um, it, I don’t necessarily use the

word a lot because it's got so much attachment to it and emotional attachment and I find, you know, um, where if you just say "I'm psychotic on occasion" they, you know, it's more easily digestible. It just, schizophrenia, you know, for other people who suffer I'm able to talk about it quite openly, um, but for people who have got their own baggage around that stuff, I'd probably say, you know, I suffer from psychosis on occasion and that's, that's a bit more digestible.

In some cases of stigma, as explored in Chapter 3, stigma becomes absorbed by the subject to the detriment of their sense of self. This enforcement of an external view onto the sufferer's subjectivity may appear unfortunate or unfair. Nathan, and one must assume many diagnosed with schizophrenia, simply does not have the skills of identity projection necessary to contradict stigma.

Nathan experienced a loss of self-esteem and, again, a related loneliness and social isolation:

RS: What happened to your self esteem?

Nathan: Well, it went down, um, I worked for a while, I worked until 2007 and I went from job to job lacking any meaningful lasting friendships with anyone. Always seen as a crazy guy and became quite lonely, quite lonely actually and um, after I was diagnosed with schizophrenia, I became lonely...

RS: OK. Are you still lonely?

Nathan: Um, well there is my mum in the room but I get lonely usually Friday nights and Saturdays, uh, Monday through to Friday is usually meetings with case managers, um, psychiatrists and psychotherapists and the PHaMs meetings and then my birds, which you can hear cheeping away in the backgrounds, they keep me company as well.

Despite this self-stigma, however, Nathan still attempts "passing" behaviour:

Nathan: I try and present myself as someone with taste, um, calm, I thank the bus driver, I say hello to the bus driver, I'm not one of those people who'll talk on the bus to other bus patrons and loud and stuff like that, I'm known by the locals and um, some people would walk right past me and act like they don't even know me, but um, then there are some people that walk up and say "Hi, how you're going?" and give me a tap on the shoulder and say "Oh, I hope you're doing well."

Analysis and Emergent Themes

There are a number of emergent themes and significant lines of analysis that develop from this chapter. As observed early in the chapter, many of the behaviours relevant to the process of

rebuilding a sense of identity are also significant to identity maintenance. In particular, the significance of ongoing interaction to self-maintenance emerged in this chapter. Such interaction typically gave people diagnosed with schizophrenia the opportunity to engage in the process of rebuilding identity and, evidently, identity maintenance. Such interaction could be with friends, family, the community or even mental health workers. As we will see below, isolation and the lack of opportunity to practice stigma management techniques may have compromised identity maintenance in some interviewees. The use of specific language also emerged as a theme in identity management. In particular, the (loaded) term “consumer” was used by a number of interviewees to avoid the more stigmatised word “schizophrenic” or “mentally ill”. The term “schizophrenic” is a loaded one. Its use to describe someone who has been diagnosed with schizophrenia suggests that the illness constitutes the totality of their identity; they do not “have” schizophrenia”, they *are* “schizophrenic”. As an alternative, “consumer” fares a little better, although we have already seen the significance of the word consumer, particularly in relation to the power of the psychopharmaceutical complex, and that analysis will not be repeated here.

The dominant theme to emerge from this chapter is a general confirmation of Goffman’s analysis as an account of stigma management, and identity maintenance. We have seen such behaviours as dividing the social world into those that know and don’t know, passing, and concealment. We may begin our analysis of this point with the suggestion that Rose’s description of people “reconceptualis[ing] themselves in terms of their own will to be healthy, to enjoy a maximised normality” may include Goffman’s stigma management behaviours. In relation to dividing the social world, we note that most interviewees were cautious about who they told about their diagnosed condition. Caitlin, for example, was careful about disclosing her condition, but was happy to attend the Leisure Club, an organisation we have seen that provides social space for people with severe mental illness. On the other hand, the theme of attending social spaces with people who share a stigmatised condition was contradicted by Greg, who negatively described such spaces as “full of sick

people". Perhaps the very stigma that some people seek to evade in such organisations also proves to be a dis-incentive to others attending. The chapter further suggests that not only are passing and concealment close to ubiquitous, but may often overlap in the behaviours of interviewees. The data indicates that insight, that important quality in recovery and rebuilding a sense of identity, may also play a vital role in passing and concealing. In particular, a realisation of one's own paranoia or faulty judgment may help the person diagnosed with schizophrenia "correct" his or her judgment and better pass for normal or conceal his or her condition. The intensity of symptoms may also play some role in passing and concealment. Those with particularly intense symptoms may find it difficult to manage stigma. This is perhaps a problem made more significant by the particular impact of schizophrenia affecting, as it often does, ability to socialise and negotiate social situations. Finally, the chapter also suggests a connection between successful self-management and self-esteem; this connection is suggested strongly by Michael's statement that "I deliver myself well, I dress well, I speak well".

Another strong theme in this chapter, and indeed in the data as a whole, lies in the relative isolation many interviewees lived in. Many, for example, had few to no friends, and might only be visited at intervals by mental health workers. As observed in previous chapters, such isolation must be understood as a result of a deinstitutionalised mental health sector. What are we to make of this isolation, however, in relation to Goffman's analysis? Certainly isolation kept interviewees in a situation where they did not have to manage stigma; did not have to pass, or conceal or divide the social world. On the other hand, social isolation radically reduced the opportunities to interact with others. As we have seen, this lack of interaction can have an important impact upon rebuilding a sense of identity, and has a similar impact on identity maintenance. As observed above, sufferers simply do not have the opportunity to develop stigma management skills. Finally, the fact of isolation highlights the importance of other people in supporting and nurturing the sufferer's ability to manage his or her stigma.

The chapter also points to the importance of the internalisation of stigma by some interviewees. Interviewees would see themselves as less capable or less worthy. Some interviewees seemed to despair at the futility of facing societal stigma. Such a finding is not entirely predicted by Goffman's analysis. The finding also suggests the sheer size and scale of the social powers that reinforce stigma. It is in relation to this observation that we may look to the final emergent theme of the chapter – the relationship between illness management and larger issues of power and social structure. We have seen that deinstitutionalisation may lead to a situation where the person diagnosed with schizophrenia has few opportunities to practice stigma management. We have seen, in a previous chapter, that stigma may negatively affect the sufferer's ability to find gainful employment. We have also seen how the scale of stigma can lead to an internalisation of stigma. Perhaps we may also find space to recognise the efforts that some interviewees went to avoid, or even contradict, stigma. In this sense the progressive illness narratives offered by Ralph may be seen, not only as stigma management, but also as a resistance to stigma. Finally, it is a difficult question whether psychiatrists themselves reinforce or reduce stigma through their interactions with the diagnosed patient. Perhaps the very fact that one has to visit a psychiatrist tends to attract stigma associated with mental illness – he, or she, is “nuts” or “crazy” or “loony”. Perhaps also, in the sense given by the social control thesis and labelling theory, the experience of visiting a psychiatrist and being diagnosed helps constitute someone with the stigmatised identity of “mental patient”. Certainly the attempt to use non-medical terms like “consumer” may suggest that the psychiatric view is stigmatising. This may form a question for future research.

CHAPTER 9

Discussion of Results

This chapter seeks to test the theoretical frameworks developed in earlier chapters against the results of interviews we have seen. The chapter explores themes that emerge from analysis of these interviews and seeks to test the limits of existing concepts and frameworks against them. The chapter draws upon results showing the intense disruption to identity that schizophrenia can cause. In light of the intensity of this disruption, the concept of “biographical crisis” is proposed. The chapter moves on to a multifaceted discussion of the main theoretical framework of the thesis, Symbolic Interactionism. This discussion brings out previously submerged, or even lacking, elements within Symbolic Interactionist thought. This includes both a focus on the need for Symbolic Interactionism to provide an account of dysfunctional identity, as well as the emotional and embodied elements of identity-related processes emergent in Chapters 6, 7 and 8. Taking up the theme of an embodied self, the chapter then reflects upon phenomenological accounts of identity disruption and rebuilding. In particular, the discussion suggests that rebuilding a sense of identity has not been adequately theorised from a phenomenological perspective, and suggests relevant new concepts such as “ontological renovation”. The uses of language by participants is then examined, particularly, in terms of power and agency. The significance of use of terms such as “consumer” is a case in point, linking as it does the protective self-description by respondents to conceptions of mental health services as products in a neoliberal economy. The theme of power and agency flows into the next section, which seeks to interrogate Foucauldian account of mental health institutions in a deinstitutionalised context. The concept of “negotiated power networks” engaged in by respondents is suggested and explored as a way to move the Foucauldian account forward. The theme of agency again emerges in the final concept developed in the chapter – “identity work”. The

concept is suggested as a broad way to capture the various behaviours respondents engage in to rebuild and maintain their identity.

Emergent Themes

In Chapter 6, the emergent theme of personal disruption was dominant; a biographical disruption generally caused by the development of schizophrenia, diagnosis, hospitalisation and relapse. The chapter noted the deteriorated thinking that can be caused by schizophrenia, as well as the use of narrative to make sense of complex experiences. In many cases, diagnosis was a turning point in the illness, coming to some as a threat and others a relief. In any case, the near-ubiquity of consensual relationships with a psychiatrist was evident. Dual diagnosis was noted as a problem facing the analysis of the experience of schizophrenia. The practice of scheduling or enforced treatment is noted as a negative experience by relevant subjects. Finally, phenomenological theory was explored as a means to comprehend breakdown of embodied self in the case of schizophrenia.

In Chapter 7, emergent themes of the importance of medication as prescribed by a psychiatrist were highly significant. Such medication typically reduces symptoms to the extent that rebuilding identity could take place. Medication could also be seen as a form of social control and often had significant side-effects. Another significant theme was the importance of symbolic interaction with others, which could take place with members of the public, mental health workers, mental health support groups, friends and family. Typically the relationship of the interviewee with family members was the most important in rebuilding identity; families could provide or withhold emotional and practical support. An accompanying, if contrary, theme was the prevalent social isolation experienced by many interviewees. For these interviewees, the infrequent interaction with mental health workers provided an entire social existence. The engagement with psychiatrists is significant in that in almost all cases it was regular and consensual, although many interviewees practiced some form of

negotiation over their treatment. In many cases, interviewees adopted psychiatric language to describe their experiences. The element of goal setting in life management also emerged as significant, although in some cases goals set seemed unrealistic. Work was important for many respondents, both as something intrinsically satisfying and as a form of interaction with others. Interestingly, of those interviewees who worked or professed a desire to work, work in the mental health sector was emphasised. Finally, engaging in religious practice seemed to give hope and the opportunity of non-judgmental social interaction to a few interviewees who engaged in such practice.

Chapter 8 explored the means by which people diagnosed with schizophrenia maintained their identity. The chapter focused on passing for normal and concealing stigmatising symbols of schizophrenia as forms of identity maintenance. In some cases concealing would involve compensating for specific symptoms, such as paranoia or inability to read social cues. The theme of dividing the social world into those “who knew” (typically family) and those who did not emerged. Likewise the chapter uncovered the fact that a significant number of interviewees attended groups with similar illnesses, and would use the term “consumer” to refer to themselves, in large part to escape the stigma of the term “schizophrenic”.

Biographical Crisis

As noted in the Theory Chapters, and reinforced in Chapter 6, schizophrenia is an illness that can bring intense disruption of a person’s sense of self and identity. The concept of “biographical disruption” is thus a valid one in the analysis of processes of identity collapse in people with schizophrenia. However, as we have also seen, this collapse can in many cases extend beyond mere disruption. An ontological dimension – a serious breach of the self – may occur, and such situation requires a more practical and accurate description.

To describe this state of affairs where identity is wholly overwhelmed we may suggest a concept: “biographical crisis”. Biographical crisis obviously draws on, and relates to, biographical disruption. However, biographical crisis suggests an experience more intense and serious than biographical disruption; an experience of existential threat. The concept also suggests the importance, and magnitude, of the task of rebuilding and maintaining a sense of identity that may face the person diagnosed with schizophrenia as he or she comes to terms with and develops strategies to cope with the illness. Indeed, having suffered identity crisis, recovery becomes in large part a task of identity reconstruction. The significance or strength of this crisis may also help explain the pervasive isolation felt by many people interviewed, even after many years of treatment and medical support; in light of biographical crisis it is simply too difficult to re-establish a pre-psychotic level of identity function and interaction with others. This appeared to be the situation with a number of interviewees. Indeed, the relationship between biographical crisis and symbolic interaction is also significant – the compromised individual must begin anew the process of learning to make symbolic gestures with a personal knowledge of the way the other person may respond, and a greater inability to see his or herself from the perspective of specific people, let alone the generalised “other”. Biographical crisis may also be a result of relapse, in which case, the patient must begin again the work of rebuilding and maintaining a sense of identity.

Having proposed this concept, it is also important to note its limitations. The primary limitation arises from the fact that identity is not at an existential level of threat in all cases of schizophrenia. People may be confused, or have delusions of reference (an experience where everyday objects or processes take on specific meaning for the subject) or experience hallucinations without an existential breakdown of the self. In such cases, “crisis” is probably too strong a word; the concept is not relevant to all cases. Nevertheless, the concept may be applied to states of chronic and mental illness other than schizophrenia, where processes of rebuilding and maintaining a sense of identity,

such as explored in this thesis, may become necessary again. Perhaps the concept could apply to dissociative identity disorder or the early stages of Alzheimers? However, it would seem that in the case of most physical chronic illnesses , identity is not sufficiently threatened to justify the intensification of the term “disruption” to “crisis”.

Symbolic Interactionism

This thesis has used the perspective of symbolic interactionism to analyse processes of identity disruption, rebuilding and maintenance in people diagnosed with schizophrenia. Much has already been said about this perspective, this theoretical position. Despite its strength, however, symbolic interactionism has a number of limitations, many of which emerge during this study. A significant issue lies in the fact that symbolic interactionism, as developed by Mead and Blumer, is a theory of self-formation, not self-dysfunction. In terms of the current thesis, symbolic interactionism fails to offer a detailed analysis of pathological processes affecting identity. The position fails to capture the entire detail and nuance of the pathological experience of schizophrenia. For example, symbolic interactionism does not fare well in an attempt to describe such dysfunctional symptoms as delusions of reference, delusions of thought transmission, delusions of bodily replacement, flattened affect, inability to read emotional cues and aural or visual hallucination.

With that said, we may go some way in a symbolic interactionist account of these symptoms by regarding them as a failure of “functional” processes of symbolic interaction. Schizophrenic symptoms represent the inverse of functional symbolic interaction. Thus the confused language, or “word salad”, that some people diagnosed with schizophrenia display may be understood as “compromised gesture”. Further, the confused or disorderly ways a patient interacts as a result of confused ideation may be understood as “compromised interaction”. Both concepts involve the reversal of an important concept in functional symbolic interactionism. Their ambit may be broad;

any type of confused or mis-directed speech may be thought of as “compromised”. James, for example, talks of relating to people through “indirect information”, believing he had dreams from other people’s point of view. Likewise, any disordered conduct arising from mental illness may be thought of as “compromised interaction”. Such concepts certainly shed some light on the influence schizophrenia can have on identity disruption, even if each concept is not present in each individual case. They may also be significant in analysing the spectrum of schizoid illnesses. Nonetheless, these concepts still face the flaw that they do not capture the precise nature of the symptom leading to failed symbolic interactionism. Compromised gesture does not encompass the details of word salad. Compromised interaction does not encompass the precise confused interactions that a person suffering the onset of psychosis in schizophrenia may display. Indeed, it seems that the best the symbolic interactionist approach can provide is a description of the *implications* of such states. For example, symbolic interactionism may not be able to describe the detail of thought transmission, but it may account for the impact on symbolic interaction and gesture that emerges from that symptom. A more successful account of schizophrenia must engage more closely with the precise symptomatology of the illness. More specifically, symbolic interactionism could refer to the symptoms set out in the *DSM-5* series:

They are defined by abnormalities in one or more of the following five domains: delusions, hallucinations, disorganized thinking (speech), grossly disorganized motor behaviour (including catatonia), and negative symptoms (APA, 2013, p. 87).

A further limit of the symbolic interactionist approach lies in its inability to engage with the subject’s emotional states. As Mead states:

Emphasis should be laid on the central position of thinking when considering the nature of the self. Self-consciousness, rather than affective experience with its motor accompaniments, provides the core and primary structure of the self, which is thus essentially a cognitive rather than an emotional phenomenon (1967, p. 173).

Emotion can play a complex role in schizophrenia. For many people, flattened affect – the lack of emotional expression – is a defining feature of the condition, as is recognised in the *DSM-5*. The inability to read emotional cues has also been emphasised in some descriptions of schizophrenia.

Alternatively, a person suffering from the related illness of schizoaffective disorder may suffer from depression, anxiety or mania, as well as such symptoms as delusions or hallucinations. The research data also suggests that a number of people diagnosed with schizophrenia have reactive emotional states; that having schizophrenia may lead them to despair, anger or fear. All these emotions make up a significant part of the experience of schizophrenia and identity. For example, a sense of assurance may help the person diagnosed with schizophrenia interact more fully with others. A sense of fear may drive the person diagnosed to trust no-one, or only trust a limited number of people. Unfortunately, such emotions are not captured in detail or nuance by a symbolic interactionism that focuses on cognition and language. Indeed, such emotions may only emerge as significant when they interfere with processes of self-formation or maintenance in a symbolic interactionist perspective. Thus, for example, the emotion of fear accompanied by paranoia may present another compromised interaction, insofar as the person diagnosed with schizophrenia may not be acting on reliable information, or absorbing the true attitudes, of the other. Fear thus becomes a process of dysfunctional self rebuilding and maintenance; another compromised interaction. The role that these emotions may play in symbolic interactionism are discussed below.

The final, related, limit in the schizophrenic experience is a failure to engage with the embodied self. Although schizophrenia is classed as a mental illness, it can involve significant embodied experience. For example, the person diagnosed with schizophrenia may experience his or her body as constituted by a foreign material, or may feel bugs “beneath their skin”. Such symptoms appear in a number of narratives of schizophrenia. Unfortunately, the data explored does not present a strong case of the embodiment of schizophrenia, although Prescott was admitted to hospital grossly underweight before he was diagnosed with schizophrenia. In any case, we may regard hallucinations as embodied symptoms, as they involve a breakdown of embodied sense and perception. This includes embodied perception of both the body and perception of the external world. The significance of the body and illness is explored in Chapter 4 – from the perspective of chronic illness

in Kelly and Field (1996) and Williams (1996), from the perspective of schizophrenia in Laing (1990) and from a phenomenological perspective. Such embodied experiences may also interfere with self and identity; indeed, a petrified or engulfed self, as Laing describes, would involve a radical disconnection from “normal” physicality, and the self that flows from that. Such embodied states are also discussed below.

The inability of symbolic interactionism to take account of emotional and embodied states is clearly problematic. Perhaps one could expand symbolic interactionism to take account of emotions and embodied states that affect self, significant gesture and the process of symbolic interaction. Such a development, however, would take symbolic interactionism far from its roots, into unexplored conceptual territory. One would need to move beyond the sole focus on symbolic interaction/gesture through language in order to account for emotions and embodied states that may influence symbolic interactions. An “emotional interactionism”, so-to-speak, would include a description of the subconscious emotional cues people read and display to each other in the course of their interaction. These cues are generally expressed through bodily states. They may vary as widely as expressing fear, confidence or desire. Emotional interactionism would thus provide an additional layer of interaction to the symbolic. The emotional situation of people interacting would also shape the symbolic interaction that such a person may make. His or her emotional situation may influence the context, colour and content of symbolic interactions. So, for example, a person suffering fear as a result of hallucinations or delusions may express this emotion through language. One interviewee, fearing the incursion of neighbours, limited his expression in outdoor situations. This development of symbolic interactionism would be well-suited to explore aspects of schizophrenia such as flattened affect, and could prove useful in understanding symbolic gestures made as a result of emotions by people suffering schizo-affective disorder, and perhaps bipolar disorder.

Again, one could also expand symbolic interactionism to take account of embodied states that affect the self. An “embodied interactionism” would recognise that people’s bodies may also be involved as the agent projecting subconscious cues to other people through “body language”. Body language would involve the vast array of expression that lies within the positioning of various body parts and, in particular, facial cues. We thus arrive at a position where significant gestures and symbolic interaction are provided with context, colour and content by the emotional state of interacting individuals, and the interaction itself takes place not only on the symbolic level, but through bodily communication. So, for example, a person suffering the embodied and emotional condition of ontological insecurity may communicate that insecurity through specific bodily interactions, such as catatonia or grossly disorganised behaviour. Incorporating these ideas into symbolic interactionism should hopefully create a more flexible and widely applicable theory of self and communication.

Phenomenology And Rebuilding Body-In-The-World

The embodied state of experiences of schizophrenia has been thematised throughout this thesis. In particular, we saw how phenomenological perspectives and, in particular, the work of Merleau-Ponty gave insight into disruptions of the embodied self; the “body-in-the-world” (a term used in the same sense as Merleau-Ponty).

However, relatively little has been said about the *rebuilding* of “body-in-the-world” *after* bodily disruption or breakdown. Such rebuilding is clearly suggested by the way many research subjects had regained a sense of bodily stability after periods of psychosis or schizoid collapse. Although Williams (1996) has discussed re-embodiment in the case of chronic illness, his writing does not account specifically for schizophrenic disruption of the body and fails to deal clearly with phenomenological concepts such as the body-in-the-world. An interrogation of the “rebuilding the

body-in-the-world”, given below, represents a significant advance on William’s account of re-embodiment, as it allows a deeper understanding of schizophrenia in the terms of phenomenology.

“Rebuilding the body-in-the-world” means, for people suffering embodied symptoms of schizophrenia, a return to the ontological state of clarity and wellness in their embodied consciousness of the world. As our study suggests, this process typically begins with the finding and reliance upon successful medication. Such medication often reduces or removes embodied symptoms, offering the first steps towards rebuilding the body-in-the-world. For those who continue to experience embodied symptoms, the rebuilding of body-in-the-world is a precarious process, typically involving an ontological accommodation of ongoing symptoms. A key element in rebuilding also lies in the task of re-learning to trust one’s perceptions after hallucination passes; in phenomenological terms, to reinstate a more usual function of perception in the body-in-the-world. Very often such rebuilding also includes a re-gaining of a pre-illness sense of time and space, temporality and spatiality; again fundamental to the phenomenological body-in-the-world. Finally, the current research suggests that rebuilding the body-in-the-world involves a return to a pre-illness sense of proprioception (the internal perception of bodily space and sensation), as well as clear, in the sense of “non-psychotic”, intentionality in actions and speech.

What is the significance of using phenomenological terminology and theory to account for processes of rebuilding a sense of identity in schizophrenia? The use of such theory makes clear the significance of the process of rebuilding identity – it can be nothing less than the return to an ontologically productive or healthy state of being. In this sense, the phenomenological approach affirms the ontological emphasis of Laing’s work on schizophrenia and confirms the importance of the concept of “biographical crisis”. Indeed, rebuilding body-in-the-world may be considered as nothing less than an “ontological renovation”. The use of this theory also helps to clarify the precise nature of re-embodiment in people rebuilding their identity in the wake of illness and diagnosis.

More specifically, the express use of phenomenological terminology (here, the words of Merleau-Ponty) provides complex and relatively nuanced tools with which to interrogate distinct aspects of identity rebuilding, particularly in its embodied nature. Thus, phenomenological concepts such as “intentionality”, “temporality” and “proprioception” help shine light on the affective and embodied aspects of the identity rebuilding process.

Language, Power And Agency

Schizophrenia is an illness that emerges, in large part, through language. Language is often the medium through which symptoms of schizophrenia express themselves; in particular, the experience of “word salad” or a mute lack of communication. Language plays an important role in the experience of the person diagnosed with schizophrenia, from diagnosis to treatment, identity rebuilding to identity maintenance. Language also entangles the ill subject in ongoing relations of power, influence and agency.

Perhaps the most significant aspect of language use in subjects diagnosed with schizophrenia is the adoption of psychiatric terminology. As we saw in Chapters 6, 7 and 8, subjects often used psychiatric discourse to describe their illness: words such as “schizophrenia”, “schizo-affective disorder” and “schizoid personality disorder”; subjects would also use the language of “symptoms” and “side-effects” to describe their experiences. The use of such language may possibly serve to “objectify” the personal challenges experienced by those diagnosed with schizophrenia. That is to say, the use of a formal vocabulary to describe the experience and treatment of schizophrenia may potentially help people disassociate or distance themselves emotionally from the more troubling aspects of the illness. This is by no means a comprehensive interpretation, however, and may be the subject of future research.

The adoption of psychiatric discourse also enmeshes subjects in a Foucauldian exercise of power/knowledge by the psychiatric apparatus; it suggests that patients have accepted their production by psychiatrists and mental health workers as “schizophrenic” subjects. However, although some subjects accepted psychiatric terminology to describe their illness and experience, some also employed certain kinds of language or discourse to negotiate or even oppose psychiatric labelling and, in particular, resist the imposition of certain drug regimes or forcible hospitalisation. We may describe such efforts as a “language of negotiation” or “language of resistance”. For example, Danielle resisted being labelled as schizophrenic after diagnosis, and spoke of being brought up believing she was “normal”. Having regard to Chapters 6, 7 and 8, such language typically escaped the more formal dialogue or discourse of psychiatric terminology, and tended to emerge in more personal language that focused on negative personal experiences of side-effects or rejection of the humiliation of scheduling.

The use of certain kinds of language also enmeshes the subject diagnosed with schizophrenia in a dense relationship with the psychopharmaceutical complex. Clearly the knowledge subjects held of their medication names, history and dosage reflect a deep engagement in the vision of biochemical illness relied upon by the psychopharmaceutical complex. Such a relationship is also evidenced in the use of the term “consumer” by subjects to describe people taking psychiatric medication. On the one hand, the term consumer may be attractive to them because it avoids the stigmatic implications of words like “schizophrenia”; let alone “mad” or “loony”. Interestingly, it seems that some subjects appropriated formal psychiatric discourse to help cope with their illness, while others spoke of being a consumer. Chapters 6, 7 and 8 suggest that generally the term is appropriated willingly, presumably adopted from the mental health support movement, and in lieu of the term “mentally ill” or “schizophrenic”, but has indirect consequences in terms of implying the “consumption” of a mental health “product” and, hence, a bio-medical understanding of the illness and submission to the power to the psychopharmaceutical complex. This phenomenon also implies a connection to

broader patterns of governance in a neo-liberal context; no longer are the ill described as patients in a welfare system, or citizens endowed with particular rights to health services, but as the consumer of a mental health product. The term “consumer” also seems to reflect the self-understanding many subjects had of their illness as a “chemical imbalance” in the brain, or fault of “brain chemistry”, addressed by the medication they consumed. This understanding reinforces the biochemical perspective on schizophrenia that underlies the psychopharmaceutical project; a perspective that offers the hope of medical intervention, but brings with it the limits of a biologically deterministic view of mind, self and illness. Indeed, we may even say, following Rose, that a “bio-medication” of the subject’s identity has occurred through the efforts of the psychopharmaceutical complex in establishing the importance of medication and colonising the psychiatric apparatus; that a “neurochemical self” has emerged.

Finally, emerging from the thesis is an emphasis on the use of language to form “illness narratives”; narratives that recount a trajectory from sickness to wellness. As we saw in Chapter 3 and Chapter 7, these narratives were broadly autobiographical and dealt specifically with questions of identity being both challenged and rebuilt. For the present discussion, however, we focus on positive or “progressive” narratives that were offered by subjects during the discussion of their illness. We may call these positive narratives “narratives of reestablishment” because they plot the subject’s path towards wellness and re-establishing a sense of identity. Such a path may be a literal “return-to-language” where the formation of narratives may be a moving-on from symptoms of schizophrenia that involve a language breakdown; symptoms such as “word salad” or a mute failure to communicate. Chapters 6, 7 and 8 also suggest that the creation and expression of narratives of reestablishment is wrapped up with the ill person’s experience of time. Typically, such narratives must include and “make sense” of a healthy life before illness, a prodromal period, the initial (and possible subsequent) disruptions so often tied to schizophrenia, and the return to a more stable state of being. Indeed, we may see the narrative act as a personal healing of the temporal breach

caused by the crisis of schizophrenia. The biographical nature of these narratives – their focus on identity – responds clearly to the biographical disruption or crisis caused by schizophrenia, whilst the emphasis on symbolic signification through narration – that is, speaking the story aloud – expressed the importance of symbolic gesture, a symbolic interactionist account of identity. These narratives also often absorbed the terminology of the psychiatric apparatus, the implications of which have already been discussed. The narratives of re-establishment present in Chapters 6, 7 and 8 also moved with the rhythms of natural speech, attesting to their deeply personal nature. Indeed, these narratives often involved the narrator as the natural “agent” of the “story”, focusing on key moments of personal transformation or insight on the path to wellness. For example, Ralph emphasised the importance of his realisation that, because he was in a psychiatric ward, there must be something “psychiatrically wrong” with him. Such agency sets these narratives apart, to some extent, from the direct influence of the psychiatric apparatus and moves beyond the biochemically deterministic schizophrenia of the psychopharmaceutical complex.

Beyond Foucault: Negotiated Power Networks

As we have seen, in the world of asylums, passing or past, social control was exercised more or less directly by the psychiatric apparatus over people diagnosed and hospitalised with schizophrenia. Disciplinary patterns of domination and production emerged. To some extent, such a power still exists in the form of power/knowledge exercised by the psychiatric apparatus, as explored above. It also exists, to a lesser extent, in the (relatively) shorter stay of people diagnosed with schizophrenia in clinics or wards before release. However, as we also have seen, such exercises and patterns have come to be challenged in a world of deinstitutionalisation and relatively effective anti-psychotic medication. In this new world, a new form of power is developing. Perhaps we may draw its outlines here.

To begin with, we may observe that the power exercised by the psychiatric apparatus becomes more remote – geographically and personally. Yet some contact is usually maintained with the apparatus through mental health workers who visit patients, or patients who visit psychiatrists. Such a situation could fairly be described as a “network” – an array of mentally ill people living alone or with family but connected loosely to more centralised mental health hospitals and clinics. This is clearly expressed in the Research Chapters, where the majority of interviewees lived alone and had sometimes only tenuous connections to mental health centres through the visit of mental health support workers. The interviewee was thus relied upon to monitor his or her own day-to-day medication and psychic state. Significantly, this form of reliance moves beyond panopticism as a disciplinary power. Under the panopticon, power was exercised through the risk that at any one time the panoptic gaze may be levelled upon the subject. In the deinstitutionalised world, a person diagnosed with schizophrenia may only be subject to a medical or psychiatric gaze at limited times each week or month. The power exercised thus moves beyond the institution; hence, again, a “network”.

To further investigate the new form(s) of power we may turn to issues of agency. Consent, negotiation and occasional resistance to treatment are amongst the themes that emerged from the various Results Chapters, and are discussed above in relation to authoring illness narratives. As Rose points out, coercion and consent blur. Such agency – negotiation, consent and resistance – can be understood as the product of the exercise of “negotiated power”. The term “negotiated power” may sound imprecise, but it is a term that captures a power that is exercised broadly by the psychiatric apparatus, and is, simultaneously, often negotiated by the patient. The patient is an active agent monitoring his own medication intake and psychic state, who must report to and be directed by a psychiatrist, but may often negotiate (within a reasonable framework) the particular terms of his or her treatment. Combining the terms networks and negotiated, we arrive at the concept of “negotiated power networks”.

Power in this structure moves beyond Foucault's institutional discipline. It is capillary, dispersed and negotiated. It is an exercise of power, but it is one consented to by the patient and continued through taking medication and monitoring one's psychological state even when not being observed. Following the argument of Rose regarding health services in advanced liberal democracies, the line between consent and coercion has been blurred. Negotiation emerges. More broadly, it is the power exercised in a service economy, where the patient (the "consumer") is consuming a mental health product of his or her own volition, having been "sold" the treatment by a psychopharmacologically-informed psychiatrist.

What are the implications of the concept of "negotiated power networks"? Certainly the concept allows us to analyse relations of power in a deinstitutionalised world, and a mental health service economy. The concept allows for a linkage to Foucault's concept of resistance – the phenomenon that emerges when the consent in negotiated power networks is removed. The concept also emphasises the active role people diagnosed with schizophrenia take in monitoring their own medication and managing their own treatment. Negotiated power networks may be overlaid by support networks of friends and family, and may be subject to the kinds of emotions and embodied experiences surrounding schizophrenia discussed in the above sections of this chapter on Symbolic Interactionism and Phenomenology. The term may be re-integrated into medical sociology more widely; it may help make sense of people who follow the advice of medical professionals away from hospitals or clinics.

Identity Work

As is stated in Chapters 6, 7 and 8, for the person dealing with schizophrenia, the process of rebuilding and maintaining a viable self can be difficult, if not seemingly impossible. We have also

seen that a number of techniques of rebuilding and maintaining a sense of identity require some active effort from the person diagnosed with schizophrenia. The diagnosed person may need to manage their illness and their life; manage friendships and family connections; cope with stigma; produce narratives to help make sense of their illness trajectory; compensate for elements of their illness and study or find suitable work. Perhaps the common theme, or themes, around these tasks is that they all relate to identity, and all require some kind of work, effort and agency. Again, these processes are not adequately described by Foucault or the other literature reviewed. How can this situation of identity and agency be theorised?

At this point the term “identity work” is suggested. Identity work may be thought of as activities furthering the process of rebuilding and maintaining a sense of identity as understood in this thesis. The term is deliberately wide in its scope, encompassing what we have discussed as illness management, life management and stigma management, compensating for symptoms or side-effects, as well as developing reconstitutive narratives and working or studying. This scope helps us comprehend and bring together various aspects of the experience of rebuilding and maintaining a sense of identity in people diagnosed with schizophrenia as explored in Chapters 6, 7 and 8. The concept is also, unlike the work of Foucault, agent-driven; focusing on the patient reducing the impact of symptoms, side-effects and stigma, while setting motivational goals and living a fulfilling life (although, of course, friends, families and members of mental health services may help with identity work). Identity work may be influenced by psychiatrists and mental health workers, but is significantly formed not as an exercise of power, but out of the patient’s desire to re-build and maintain identity, and improve his or her quality of life. There may also be a mutually beneficial relationship between symbolic interactionism and identity work – successful identity work may help the use of significant gesture and symbolic interaction by the person diagnosed with schizophrenia.

Before concluding, we must briefly consider how “identity work” differs from “biographical work” (discussed in Chapter 3). Although the concepts are similar, identity work is aimed more squarely at the experience of schizophrenia, rather than chronic illness more widely. As we have seen, schizophrenia can involve a biographical crisis, a breakdown of the self, in the context of which identity work becomes more salient. The concept also involves more than biographical factors – it includes attempts to mitigate stigma, symptoms and side-effects. The term also carries the implication that many aspects of the study of identity processes in schizophrenia can be understood through a single, broad concept. This should make studying the various phenomena involved more practical and, hopefully, meaningful. The concept may also have use in psychiatric conditions such as dissociative identity disorder, or chronic illnesses occasioning biographical disruption, where personal identity is also highly compromised.

CHAPTER 10

Conclusion

This thesis has sought to answer the question of how people diagnosed with schizophrenia re-establish or maintain their identity in light of their illness, diagnosis and treatment, and how relations of power inform this process. The thesis engaged in a qualitative case study of twelve people with schizophrenia, using semi-structured interviews as the primary research method. This method has provided rich data in response to the research question. The value of this thesis lies in showing how people with schizophrenia can actively re-build a shattered self, and maintain that self under difficult circumstances. This thesis also seeks to re-think and revise some of the available conceptual tools for understanding the self and other, and to make sense of processes of identity disruption, rebuilding and maintenance in people diagnosed with schizophrenia. The thesis intervenes in the sociology of chronic illness, proposing the concept of biographical crisis; contributes to symbolic interactionism, with the concepts of compromised gesture and emotional interactionism; and engages with the theorisation of serious mental illness, by deploying developments in the fields of phenomenology and advancing the concept of identity work. Finally, the thesis contributes to the theorisation of power relations in serious mental illness, with the concept of negotiated power networks and an analysis of the role of language and power.

Synthesising Results And Discussion

The data uncovered by this research is deep and resonant. Interviewees shared significant, personal stories with the interviewer. These stories provided fertile material with which to address the research question. Stories of identity disruption, rebuilding and maintenance could be found within

the pages of data collected. Vital experiences of mental illness, of isolation, of stigma and of power emerged. What follows is a concluding summary of the main points of that research, made in Chapters 6, 7 and 8, integrated with the theoretical contributions made in Chapter 9.

Interviewees generally faced grave disruption to their lives and biographies through their experience with schizophrenia. Encounters with the illness itself, as well as with diagnosis, hospitalisation, the psychiatric apparatus and the psychopharmaceutical complex all contributed to the disruptive nature of the schizophrenic experience. Typically, interviewees experienced a significant breakdown in their “self”, as theorised in Mead and Blumer’s work in the symbolic interactionist literature. The symbolic interactionist literature was also extended to account for the disruptive, or dysfunctional, experience of self-breakdown. The concepts of compromised gesture and compromised interaction helped make sense of the breakdown of the self in schizophrenia, and contributed to a richer reading of symbolic interactionist theory. Such was the intensity of the disruption of schizophrenia that many cases came to constitute a biographical crisis; an ontological breakdown of the very being of the interviewee. The embodied, emotive nature of this disruption also emerged, and was explored through the use of phenomenological theory, as well as the proposal of embodied, or emotional interactionism. The issue of isolation-as-disruption also emerged for a number of interviewees who lived alone or rarely socialised. The power of the psychiatric apparatus also began to become clear, insofar as diagnosis with a psychiatrist and hospitalisation contributed to these processes of identity disruption.

Rebuilding a sense of identity was revealed to be a complex, subtle process involving a number of factors. The primary role of medication cannot be underestimated. Medication, in many cases, dampened symptoms of schizophrenia sufficiently for the person diagnosed to engage in everyday processes of symbolic interaction. Typically, meaningful interaction with others, making meaningful gestures and the internalising of the view of the general “other”, as predicted by symbolic

interactionist theory, was a vital aspect of the process of rebuilding identity for interviewees. Such interactions included (inter alia) relations with family and friends, mental health professionals, other sufferers and religious communities. Processes of rebuilding identity involved the sufferers in a course of active behaviours aimed at ameliorating the impact of their illness. Typically this included negotiating prescriptions of medication, as well as illness and practical life management. Such agent-driven attempts at self-management were described collectively as identity work; a concept that may hold broader significance outside the field of rebuilding a sense of identity in schizophrenia. The ontological nature of the breach-in-self that interviewees sought to fill led the researcher to inquire into phenomenological readings of schizophrenic symptoms. In particular, the thesis makes the suggestion of re-establishing the body-in-the-world, or ontological renovation, as concepts to guide our understanding of processes of rebuilding identity. The use of language provided a revealing lens with which to understand efforts towards rebuilding identity in people diagnosed with schizophrenia. Typically interviewees would adopt psychiatric discourse to describe their situations and experiences of rebuilding a sense of identity, involving again the influence of the psychiatric apparatus. However, language use proved significant for other reasons. In particular, the use of the term “consumer” by interviewees using psychiatric medication brought with it a complex relationship to the mental health market and the psychopharmaceutical complex. The use of illness narratives involved interviewees in a personal re-telling, or re-framing, of their experiences; a re-framing often involving themselves as an active agent who sought help, negotiated medications, searched for work, and so forth. The issue of agency was one which emerged in the theorisation of power exercised by the psychiatric apparatus in a context of psychopharmaceutical interventions and deinstitutionalisation of psychiatric service provision. The term “negotiated power network” captured the relationship of the interviewee who often lived alone, but regularly took psychiatric medication and was visited by mental health workers, or visited a psychiatrist. The lone living of interviewees – their comparative isolation – also emerged as a strong theme.

Finally, interviewees engaged in a number of behaviours to maintain their identities. Strictly speaking, such identity maintenance involved a number of the same processes as rebuilding a sense of identity; managing medication and doctor's appointments, for example, contributed both to interviewees re-establishing a sense of self as well as maintaining such a self once established. Identity maintenance also involved distinct processes of stigma management. Interviewees managed the considerable stigma of having schizophrenia by dividing their social world into people who knew and did not know, by passing for normal, and by concealing the more noticeable aspects of the illness, such as paranoid thinking or misjudging affect. Again, the opportunity to practice these skills was important to many interviewees, and issues of isolation sometimes mitigated the processes of identity maintenance they could take part in.

Directions for Future Research: Towards a Broader Sociology of Severe Mental Illness

During its exposition, this thesis has developed what is, in many ways, a sociology of identity for people suffering schizophrenia. Further research and theorisation could clarify or deepen the understanding of issues pertinent to the study of schizophrenia. In particular, a more rigorous, perhaps quantitative study might examine the role of the various factors identified here in the process of rebuilding viable identity. Of course, such a study would require a more exact measure of identity function than the fairly broad concept offered by symbolic interaction and used here. A larger study could also address the limitation in this thesis that, perhaps, only subjects who are better coping with the illness have responded; it would be important to gain a view of the experiences of people who are not as resilient or successful.

However, whilst our academic journey has, hopefully, been rewarding, it could also perhaps contribute to wider sociological questions. This research and the theoretical work accomplished during this thesis may hold lessons or contributions towards a wider sociology of severe mental

illness. To investigate this issue we may engage with one of the major sociologists of mental illness, Erving Goffman, and ask the heuristic question: *If Goffman were alive today, what would he write about severe mental illness?* The answer to this question would certainly be multi-faceted and wide-ranging. Many relevant responses have already been treated in this thesis, and so are only mentioned in passing. Other implications may provide interesting issues or foci for future research, and these are explored below.

Certainly the response to the heuristic question would involve coming to an understanding of deinstitutionalisation. Simply put, severe mental illness at the time of Goffman's writing was generally responded to (or "treated") in asylums and wards. People with schizophrenia or bipolar with psychotic symptoms, amongst other severe disorders, were locked up in "total institutions", and these institutions governed their subjectivity and social world. The situation now, in Australia, is very different. People with severe mental illness are usually released from hospital or the clinic within some weeks or months of institutionalisation and their treatment will generally involve them living in the community; with families, community support or alone. With that said, we must at least acknowledge that temporary incarceration in a mental health institution may still affect many people with severe mental illness, and practices such as electro-shock therapy and community treatment orders still exist. The old critiques of the mental health sector may still hold some sociological sting, although not as poignant as they once were. Nevertheless, the sector is deinstitutionalised and one may ask, what are the implications of deinstitutionalisation seen through Goffman's eyes for a broader sociology of severe mental illness?

Part of Goffman's value as a researcher comes through his precise and revealing descriptions of everyday behaviour and interaction. This focus on the everyday, the "micro", in a deinstitutionalised environment has served this thesis well and could certainly apply to a broader sociology of severe mental illness. We have already seen that a close, interpretive and qualitative research approach

may yield interesting data. Symbolic interactionism provides a sensitive account of meaning, interaction, mind and identity that can be applied to those suffering mental illness, and perhaps also to those around them; an account strengthened by the moves in this thesis to recognise compromised gestures or interaction and emotional or embodied interactionism. Indeed, these suggested concepts could possibly also be tested and refined in a more controlled setting. The close focus on interaction in this thesis, and carried by Goffman, could also provide insights into power relations affecting people with severe mental illness; the following of medical regimens; and the nature and effect of stigma.

We may ask, however, whether there are any forms of close interaction that might occur in the sociology of severe mental illness that are not discussed in this thesis? Three possibilities may be identified. Firstly, it seems possible, and perhaps likely, that the stigma associated with mental illnesses such as bipolar disorder, severe depression or anxiety is less than that associated with schizophrenia. Schizophrenia is still commonly misunderstood as referring to dissociative personality disorder (“multiple personalities”) and/or significantly increased predisposition towards violence. Perhaps people with bipolar, severe depression or anxiety would be less concerned with passing or concealing their stigma? Second, there is a possibility that in some cases of severe mental illness the sufferer may *not* visit a psychiatrist, instead consulting a general practitioner or even a branch of alternative medicine. It remains to be seen whether this kind of consultation would take a different form to the relationship with a psychiatrist, and particularly whether it reduces the influence of the psychiatric apparatus over the mentally ill. Finally, it seems likely that in a number of circumstances people suffering severe mental illness that is not schizophrenia may interact with others in a way that is more complex and active as they might not suffer the cognitive deficit that often comes with the onset of schizophrenia.

Another important aspect of Goffman's approach is his critical, sociological eye. There is no doubt he would offer a critical account of the deinstitutionalised environment for the treatment of severe mental illness. As also noted in this thesis, a critical history of deinstitutionalisation in Australia is yet to be written. However, we have already seen that deinstitutionalisation may lead to isolation of sufferers. We have also seen that the transfer of caring responsibilities from asylums to members of the community, especially families, may engage a gendered division of labour in caring for the sick. Certainly further research might be conducted to engage with both of these issues. Other critical points also arise. There is the possibility that, in a deinstitutionalised environment, there is an incentive to discharge early, and people suffering severe mental illness may be released before attaining full stability in their illness and the ability to engage with public and communal support. There is also the critical possibility that sick people outside the asylum may not have the financial or social capital necessary to source medication or work, or find places to live. Indeed, without sufficient communal support, homelessness or "trans-institutionalisation" may occur, where the sufferer moves through boarding houses, refuges or even jail; a form of "institution-outside-the-institution". The connection between severe mental illness and homelessness is indeed a significant social and political problem, and deserves future research.

A successful, broad sociology of severe mental illness in a deinstitutionalised context would also need to focus to a significant degree on the experience of recovery. What is recovery? How do people with mental illness define recovery, and does this differ from their psychiatrists, GPs or mental health service providers? How do "illness trajectories" play out for different mental illnesses experienced by people in different geographical and socio-economic locations? Perhaps the answer to these questions can be aided again by a theoretical move made in this thesis. More specifically, the concept of "identity work" could provide a template for the kind of interactions the severely mentally ill person outside the clinic or ward sometimes makes towards recovery. The term "recovery work" springs to mind; such a concept could, like identity work, take account of the

various prosaic and everyday interactions that a severely mentally ill person may engage in with the end of mental health recovery in sight. We may make the provisional observation that such recovery work would probably involve sourcing, paying for and taking regular medication; setting up and relying on familial or community support groups in lieu of institutional observers and enforcers; engaging in fruitful symbolic and emotional interactions with others; and engaging in the kind of activities such as exercise or meditation that may lessen the intensity of their illness.

The analysis of recovery can also be related, perhaps inversely, to one of the issues touched upon, but not analysed at depth in this thesis – the attempts of people with mental illness to take their own lives. A micro-level, interactionist approach could help shed light on “warning signs” and dangerous behaviours of people with mental illness at risk of suicide (see, eg, Schwartz and Smith, 2004). One may wonder whether suicide was more difficult for people caught up in, and constantly observed, in a total institution? Perhaps the life alone outside the asylum walls without adequate community support, for some, may contribute to the darker emotions that lead to ending one’s life. At this point, we may complement the micro-focus with a wider sociological lens, taking in larger social structures and socio-economic trends in relation to suicide. Durkheim’s seminal work *Suicide* (2002) in this regard could provide interesting insights.

With regard to the issues of recovery and suicide, a broad sociology of severe mental illness could take advantage of another important argument implicit in this thesis, and one that seems to hold true in a deinstitutionalised context. That is to say, a sociology of severe mental illness could recognise that sociological factors are vital in not only rebuilding a sense of identity in people with mental illness, but may in fact play an important part in recovery. At one level, this insight may seem obvious or simple – a person without the socio-economic position to afford medication may be stranded with their illness. In the case of mental illnesses such as severe depression or anxiety, particular relationships may provide support for people to recover. However, and in an important

sense, this thesis has argued that the sociological determinants of rebuilding and maintaining a sense of identity move beyond the practical and may, in and of themselves, contribute to positive identity outcomes. The social interaction of the person with schizophrenia may help him or her to rebuild and maintain viable identities. Such an argument is borne out by non-medical, psychological treatments that treat cognitive aptitude and the ability to recognise affect in schizophrenia. In this sense, an implication of the thesis has been to emphasise that merely being medicated and/or hospitalised are not sufficient, on their own, for full recovery – a sick patient could and should engage in positive social interaction where possible. The monopoly of the biomedical paradigm on recovery processes could and should be widened to include sociological effects. This insight could prove foundational for a broader sociology of severe mental illness.

Having explored a number of critical issues for future research towards a broader sociology of severe mental illness, we may ask whether further work remains to be done at the broad, “macro” level – at the level of society, or state, or globe? Whilst good work on the political economy of recovery of schizophrenia has been done (see, particularly, Warner, 1985), we may still ask whether these patterns of recovery hold for other severe mental illnesses and, in particular, whether the political economy of recovery is altering in a globe that is itself developing and evolving? For example, one may question whether effective mental health institutions are being built or provided for the expanding middle classes of India or China? Is the psychopharmaceutical complex entering these new markets? We have also seen in Foucault’s (1988) *Madness and Civilization* an analysis of the relationship between “madness” and civilization. We may ask, however, whether his insights still ring true, and examine the deep cultural and ideational significance of madness and its treatment in Australia, the West, and globally.

Concluding Thoughts

Schizophrenia sadly remains a persistent, chronic and severe mental illness for a significant portion of the population. Whilst this thesis may have engaged with people whose illness did not limit them as much as others, there would seem to remain a large population of people living with the illness in dire situations. Many may live in isolation, without community support, or without familial understanding. Clearly, in a deinstitutionalised world and a world of stigma, community support and general education about the illness has become more important. Whilst the New South Wales State government has made, during the writing of this thesis, commitments to further fund community support for people with severe and persistent mental illness, it seems much still needs to be done. In any case, the voices of people with schizophrenia are still largely unheard, and there lie valuable pathways – not only in relation to identity, but to the illness and recovery more broadly – for sociologically-influenced approaches to help give these voices volume. Hopefully this thesis has provided some such voice.

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