Chapter 2

The subjective experience of madness

One of the central points we want to make in this book is that consideration of the subjective experience of madness has much to contribute to our understandings of madness. Indeed, we would go further than this: our position is that any understanding of madness which overlooks subjective experience will inevitably provide an incomplete and, ultimately, inadequate conceptualization of the experience. This is, we believe, true of much human experience, but particularly true of madness given that it is the individual's subjective experience (such as hearing a voice, or having a 'delusional' belief) that is at the heart of how we define madness when we use terms such as psychosis and schizophrenia. To try to understand madness without recognizing, acknowledging and incorporating the subjective aspects of the experience into our understandings is an impossible task, doomed to failure.

Despite this, it seems to us that much of the scientific literature and research in this area has tried to develop theories of madness that pay little heed to subjective experience. The voice of lived experience has been all but extinguished, and, as a consequence, the theories we encounter are deprived of the human aspects, and the humanity, of the experience, managing to make those who have such experiences sound barely human, as if they were part of 'a logically distinct species' (Bannister 1968). We should keep in mind that theories of madness are not mere academic theories, with little impact on practical matters. On the contrary, how we understand madness informs and shapes the kinds of clinical approaches offered to those who may find their experiences troubling. Understandings of madness also influence how lay people respond to these experiences (see Chapter 4). If, as we contend, these understandings are impoverished or inaccurate as a result of neglecting the subjective experience, then we should expect that our clinical approaches will be similarly impoverished and less helpful than they could be.

Another consequence of the exclusion of subjective experience is that those who have first-hand acquaintance with the experience are deemed unable to contribute to our understandings of such experiences. They are effectively silenced, excluded from discussions about what the experience is, about what the experience means and about how to offer help to those who find the experiences troubling. This seems patently bizarre to us: as if only those who had never tasted chocolate were really able to explain what it was like, or as if being, say, a Scot, excluded one from the discussion of what it means to be Scottish. Surely, such a scenario would seem absurd, unhelpful and unacceptable in almost any other domain of human existence and experience. Yet, this is exactly the scenario we find in the all too human experience of madness: those who are most intimately acquainted with the experience have been sidelined in our efforts to understand and work with the experience, although there are signs that this might be changing, as consumers of mental health services come to have greater input into how such services are organized and delivered (Deegan 1996; O'Hagan 2001).

In this chapter we will put forward our case explaining why we believe subjective experience is crucially important, despite having been largely neglected. We want to challenge the notion that madness can be made sense of by bypassing the subjective aspects of the experience. To do this we will show, first, that this is indeed a neglected area of study, before going on to look at the research that has been done in this area, the findings of which clearly demonstrate the importance of such research. In subsequent chapters, we will look in more detail at other aspects of the subjective experience of psychosis.

To begin this discussion it is worth briefly considering how it might have come to pass that subjective experience came to be excluded from scientific investigations into human experiences such as madness. From its origins the scientific method has valued investigations which emphasize objective observation and measurement over subjective experience. So long as the focus of scientific investigations is inanimate objects and matter, one might have few objections to this approach, given that, we assume, inanimate aspects of the material world, such as sub-atomic particles, gravitational forces, and electrical currents have no subjective experience of their own being. However, in the nineteenth century, these same scientific methods, which were proving so successful in the study of the material world, were adopted by health researchers and social scientists, whose focus was not on inanimate objects bereft of subjectivity, but was, rather, on a quite different animal, characterized, one might argue, by its capacity for reflecting on its own experience: the human being.

The person most commonly identified as responsible for importing this perspective from the natural sciences into the social sciences is the nineteenth-century French thinker, Auguste Comte. Comte developed his influential philosophical doctrine of 'positivism', at the core of which are two principles, namely, that general 'facts' about human beings can be developed and that these facts must be based on scientific (or 'objective') observations. This position tended to downplay, or even exclude completely, the role of subjective experience as part of the scientific enterprise. As noted in Chapter 1, the twentieth century witnessed challenges to the 'positivist' perspective, particularly from those who embraced the notions that meaning and interpretation are central to the study of human beings, within what has been called the ‘interpretive turn’ within the social sciences (Rabinow and Sullivan 1987). While it is not our intention to discuss these theoretical issues in detail here, we mention it now to acknowledge the broader context within which the question of the significance or otherwise of subjective experience is located. Our position, which we hope is clear by now, is that if we truly want to understand such a complex human experience as schizophrenia, we need to embrace both conventional ‘objective’ scientific research and research which is sensitive to subjective aspects of the experience, such as what it means to the individual concerned.

The status of research into the subjective experience of madness

So, let us now look at the position of research into subjective experience in the area of schizophrenia. We have already argued that this occupies a marginalized role, with there being relatively very few investigations into subjective experience. We now want to substantiate this claim, one which we are not the first to make. In a review of research in this area, Lally (1989) pointed out that within mental health there is a general lack of research into patients’ perspectives. More specifically, in the area of psychotic experiences this lack of research is even more pronounced. Molvaer et al. (1992: 210) examined the research in this area and concluded that ‘research dealing with patients’ own attributions for their illness has been virtually non-existent’, a conclusion very similar to the one reached more recently by Drayton et al. (1998: 270), who complain: ‘There is a paucity of research concerned with the individual’s psychological adaptation to psychosis.’

This neglect of research into clients’ understandings of and relationships with their experience is somewhat curious, when we remind ourselves that in the area of mental health diagnoses depend almost entirely on the clients’ own description of their experience (as opposed to being derived from diagnostic biochemical tests such as are used in other areas of medicine: see Newnes, (2002) for a discussion of this matter). It seems almost as if the client can be (indeed *must* be) relied upon to provide a history and description of his or her experience, on which the diagnosis will rest, but, once the client has provided this information, he or she is then viewed as having little to contribute towards understandings of these experiences. The paradox here is that while diagnosis depends upon seeing the client as a valuable, indeed necessary contributor to the process, once the client has been diagnosed with a psychotic illness, this *ipso facto* seems to render him or her unable to contribute to the discussion regarding what this condition means.

Though there is a general lack of research in this area, a few notable and influential writers have made a strong case that this is an important clinical and research consideration that ought not to be overlooked. In his classical text Jaspers (1963) dedicated an entire chapter to the patient's attitude to illness and made some effort towards developing a classification of the individual's ways of understanding and responding to psychotic experiences. Jaspers (1963: 417, original italics) argued that 'Much can be learned from *patients' own interpretations*, when they are *trying to understand themselves*.'

Another early text which drew attention to the importance of clients' understandings was by Mayer-Gross (1920, quoted in Dittman and Schuttler 1990). Mayer-Gross considers the opinions of people diagnosed with schizophrenia and suggests a classification for how the individual responds to their experience. Mayer-Gross (1920) proposes five ways in which the client may respond to the experience: 'despair', 'renewal of life' (seeing the experience as offering this), 'shutting out' (as if nothing happened), 'conversion' (where the psychosis is viewed as a revelation) and 'integration' (of the experience into the notion of self). These terms have not been adopted within clinical practice or research. More recently, in other important psychiatric texts, Sims (1988, 1994) argues that a full and proper assessment of the client's difficulties must involve a detailed phenomenological exploration of the client's subjective experience, and an empathic appreciation of the same. Sims (1994: 445) makes the point that within clinical practice 'There is a great need to acknowledge, have respect for, and use in treatment, the patient's *own* experience'. Promisingly, this call is echoed in an editorial in the *American Journal of Psychiatry*, where the writers suggest that those responsible for updating the diagnostic manual should give serious consideration to incorporating subjective aspects of experience within DSM-V (Flanagan et al. 2007).

Sadly, these calls to value the client's own experience have not been much heeded in either research or in clinical practice. One of the ways in which the neglect of the client's experience is manifest is in the lack of an accepted well-developed language to refer to, describe, or categorize clients' understandings of and responses to their own experience. This leaves us in the kind of predicament described by the philosopher Ludwig Wittgenstein (1922) where our lack of language limits what we can say. This point is identified as an obstacle to research in this area by American psychiatrist and professor of medical anthropology and cross-cultural psychiatry Arthur Kleinman (1988), who notes:

> Clinical and behavioral science research also possess no category to describe human suffering, no routine way of recording this most thickly human dimension of patients' and families' stories of experiencing illness.
> (Kleinman 1988: 28)

One rather simple way to investigate the question of whether or not subjective experience is given adequate attention is to look at research into schizophrenia, and see what proportion of this focuses on subjective aspects of the experience. This is possible through the use of electronic databases such as MEDLINE and PsycINFO, which collate research into a wide range of health and psychological issues and are generally accepted as providing comprehensive access to the scientific literature in the field. We used both these databases to consider the status of research into the subjective experience of schizophrenia. We searched these databases, using the search terms 'schizophrenia' (which is the term most commonly used in scientific studies) and 'subjective experience' (which yielded more hits than similar terms such as 'subjectivity' and 'first-person accounts'). We present our findings from these searches in Table 2.1.

What we can see clearly in Table 2.1 is that subjective experience is very much on the periphery of scientific investigations into schizophrenia. In MEDLINE (covering the period 1966 to 21 June 2008), only 0.17 per cent of the total schizophrenia literature is related to subjective experience. Using PsycINFO (covering 1806 to June 2008), we find this figure is a little higher, at 0.33 per cent. This increased figure in PsycINFO is probably attributable to the fact that the database covers social sciences, whereas MEDLINE has a more medical orientation. Clearly, both figures indicate that research into subjectivity occupies but a very small proportion of the literature on schizophrenia, so demonstrating the marginal nature of this research. However, this table also shows that when we limit our results to specific time periods we find that there has been a growth of research in this area, both in terms of absolute numbers, and as a per cent of total schizophrenia research. In MEDLINE we find the proportion of schizophrenia research involving subjective experience has more than doubled each decade, from 0.01 per cent (1 article) in 1965–1975, growing to 0.3 per cent (69 articles) in 1995–2005. A similar pattern is found using PsycINFO, with the figures growing from 0.07 per cent (4 articles) for the decade to 1975, to 0.53 per cent (119 articles) in the decade ending 2005. There is a clear trend of increased interest in this area, though we should not lose sight of the fact that these figures are very small, in both percentage figures and in absolute terms.

It seems reasonable to ponder why it might be that we find this neglect of the client's understanding within mental health research and practice. One explanation is proposed by Mechanic (1972), who suggests that in mental

Table 2.1 Showing % of schizophrenia research which investigates subjective experience (numbers of articles in parenthesis)

	MEDLINE	*PsycINFO*
Totals	**0.17%** (109)	**0.33%** (184)
1965–1975	**0.01%** (1)	**0.07%** (4)
1975–1985	**0.05%** (5)	**0.13%** (11)
1985–1995	**0.12%** (18)	**0.24%** (36)
1995–2005	**0.30%** (69)	**0.53%** (119)

health care it is more difficult to separate the attribution from the entity about which the attribution is made. That is, the client's understanding of the experience, and the experience itself, given that they are both essentially psychological processes, are difficult to disentangle, and, perhaps as a consequence of this, the client's understanding of the experience tends to be overlooked by clinicians and researchers.

Kleinman (1988) offers a different and, to us, more persuasive argument, when he locates the problem more squarely within the realm of modern medicine and medical training (rather than being somehow inherent in the experience, as Mechanic (1972) seems to suggest). Kleinman argues that the biological focus within medicine and the kinds of practice that this engenders precludes inquiry into the meaning of the experience. Kleinman (1988: 17) suggests that the tendency to overlook the patient's perspective is developed in medical training where clinicians 'have been taught to regard with suspicion patients' illness narratives and causal beliefs'. A similar position is taken by Jennings (1986: 866), who argues that 'The emergence of biomedicine's remarkable effectiveness in curing disease has apparently been accompanied by a relative neglect of patients' experience of disease.'

Equally critical of the neglect of the client's perspective, though proffering another take on why this might be so, is the late Loren Mosher, who ran the successful Soteria House project in San Francisco from 1971 to 1983, which showed that non-medically driven treatment, from non-professionally trained staff who show respect and tolerance for psychotic experience, is effective (Mosher 2001; Mosher et al. 2005). Mosher suggests that traditional, narrowly biological medical approaches to people who are psychotic may have been developed to allow clinicians to keep the troubled person at a distance arguing that: 'When looked at contextually, these interventions seem to be designed to allow the rest of us to avoid having to deal with these persons' humanity – that is, their subjective experience of psychosis and its effect on us' (Mosher 2001: 389).

Mosher's position is that ways of understanding madness which emphasize diagnoses, by using terms such as schizophrenia, reflect an understandable human tendency to want to distance oneself from the confusing and painful experiences of others, but this also has the dehumanizing effect of negating the value of the person's subjective experience. He advocated that staff working with psychotic clients should above all aim to understand the client's experience and respect the client's understanding of the experience. Sadly, despite research showing that Soteria was effective, it was closed down due to lack of funding in 1983. Although currently there are a few Soteria-like facilities in Europe (Sweden, Switzerland, Germany and others) which operate with a similar philosophy, such facilities remain very much on the periphery of mental health services for those who experience psychosis, which are dominated by medically oriented services, which operate within the diagnostic framework, with its tendency to emphasize categorization of clients' experiences and which, as we have seen, pays little serious attention to the client's subjective experience.

What can be done?

How then might we overcome this tendency to neglect the subjective experience of the individual who experiences psychosis? However we might go about this, we need to heed Mosher's (2001) point that approaching the subjective experience of a troubled soul may, in itself, be distressing to some and therefore appropriate training and support will be necessary. It seems to us that addressing this neglect will involve adopting an attitude to psychosis/madness which recognizes it as an essentially human experience and similarly acknowledges that those who experience psychosis are 'experience-based experts' who have valuable contributions to make. Fully acknowledging these points will entail embracing methods of conducting research and clinical practice which are congruent with these principles. These issues will be further explored when we discuss research into subjective experience (Chapter 3) and when we outline one way of conceptualizing psychosis which explicitly values various forms of expertise, including experience-based (Chapter 6).

Why is subjective experience important?

We will now move on to consider some of the reasons why we believe subjective experience of psychosis is important, beginning with an ethical argument, before moving on to consider empirical findings which illustrate quite convincingly that to understand and work with psychosis we need to take subjectivity into account.

Ethical arguments

A general ethical position arguing for the importance of attending to subjective experience is stated forcibly by Fulford and Hope (1993: 691) who argue that 'understanding the patient's actual experience is the basis of sound medical ethics': attending to the patient's understanding is a *sine qua non* for ethical medical practice. In a more general sense, the phenomenological philosophical position, as espoused by the likes of Husserl (1962), operates from the starting point that immediate experience is necessarily unique and that to be human is to interpret or 'thematize' one's experience: to be human is to make one's unique sense of one's own unique lived experience. Failure to treat another individual as having this capacity is to fail to treat that person as fully human; surely not a basis upon which an ethical medical practice could be based. Though Husserl's concern was more with the human condition in general rather than the more specific domain of medicine, his perspective has been adopted within medical research by the likes of Kirmayer who summarizes this argument nicely:

> Caring begins with accepting the phenomenal reality of the patient's suffering, including its moral significance to the patient and others. Accepting the patient as person leads to a willingness to explore the personal meanings of distress beyond the theories of biomedicine.
>
> (Kirmayer 1988: 82)

Another concept relevant here is Shotter's (1981) notion of 'authoring'. Shotter argues that whether or not one is allowed to be the author of one's own experience is more than just a psychological or sociological issue. He argues that 'authoring' should be thought of as a moral right, proposing that 'In a moral world, no one but the person in question has the status, the authority, under normal conditions, to decide what his experience means to him' (Shotter 1981: 278).

Shotter goes on to suggest that this right is a central part of autonomy and that 'authoring' extends not only to establishing for oneself what one's experience means but also being able to share this understanding with others: 'To be autonomous . . . is to be accorded the right of expressing one's self, of telling others one's thoughts, feelings, and intentions, and the right to be accorded their author' (Shotter 1981: 279). This theme is echoed by Lakoff (1995), who looks more at the impact on the person, arguing that being denied the ability to define one's own experience 'is to be deprived of self-knowledge, and of full consciousness' (Lakoff 1995: 33). Another consequence of not being able to define and describe one's own experience is what Roberts (1999b) refers to as the 'silencing' of the individual's story. These issues relating to 'authoring' are of considerable importance in our own research into the client's experience of psychosis and will be discussed further later (Chapter 3).

In short, we believe there is an overwhelming ethical argument for acknowledging the importance of the client's understanding of his or her experience of psychosis, and that to fail to do so would be to fail to meet one of the first requirements of an ethically sound clinical practice. Even if one were to accept that there are aspects of the experience of psychosis which are difficult, even impossible, to articulate and further that those who experience psychosis may be compromised in their capacity to express this experience clearly and fully, this does not, in itself, render this ethical argument invalid. The ethical importance of being author of one's story, and of having that story heard by others, remains true even if one accepts these limitations. However, lest this ethical argument on its own is not convincing, let us now consider some of the empirical findings from research into subjective experience which further underlines its importance.

Empirical arguments

In this section, we will provide an overview of research which demonstrates relationships between important clinical variables and the subjective experience of psychosis. While there are many aspects of subjective experience that one can study, areas which are commonly investigated include the individual's understanding (or 'explanatory model': how the individual explains the experience), the individual's attitude to and relationship with the experience, and the individual's phenomenological descriptions of the experience. As we will see research in each of these areas provides us with important insights into the nature of psychosis, and gives us significant pointers regarding how to work clinically with those who are troubled by psychosis.

Explanatory models: how the individual understands the experience

The concept of 'explanatory model' comes from the work of Arthur Kleinman, who has written extensively about explanatory models, particularly in relation to chronic physical illness (for example, Kleinman 1986, 1988, 1993). Kleinman defines explanatory models as 'the notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process' (Kleinman 1988: 121). In the same book, Kleinman proposes that illness experiences must be rendered meaningful by the individual and that developing meaning for an illness experience helps turn a 'wild, disorganized natural occurrence into mythologized, controlled, cultural experience' (Kleinman 1988: 55). Explanatory models are not simply beliefs that one has about an experience of illness, but are broader than this, being frames, usually provided by one's culture, that render such experiences meaningful (Good 1986). Explanatory models can be thought of as a story that the patient and significant others construct and tell to give coherence to the events and course of suffering. These stories tend to be derived from a particular cultural context, are often tacit rather than explicit, and may at times be contradictory and may shift in content.

Perhaps the first question one might ask regarding clients' explanatory models for psychosis is whether or not individuals do in fact develop understandings, or models, of their experience. Research findings are consistent in this regard: the vast majority of clients of mental health services (whether new presenters or longer standing clients) do indeed have explanatory models for their experiences. For example, Angermeyer and Klusmann (1988) carried out survey and interview research in Germany, asking approximately 200 patients with a diagnosis of schizophrenia if and how they made sense of their experience. They found that the majority of clients had some notion of likely causes of their experience: 74 per cent expressed their explanation in interview, whereas 93 per cent of their sample were able to identify their own particular understanding of their experience from a checklist of possible causes. Similarly, Bannister (1985) studied explanatory models of 60 patients newly admitted to a British psychiatric hospital and found that patients had already developed fairly sophisticated understandings of their experience within the first three days of admission, with only 18 per cent saying it was a ‘total mystery’. Further, Dittmann and Schuttler (1990) report that among patients with a diagnosis of schizophrenia in Germany, when asked about causes of their experience, only 12 per cent were unable to offer an explanation. It is clear then, that those who have psychotic experiences do indeed strive to make sense of and build explanatory models for their experience.

An important point to make here is that explanatory models, just like stories, are not merely explanations which have no impact on the experience itself. Explanatory models are best thought of as ‘constitutive’ in that they are an important dynamic component of the whole experience. An individual’s understanding not only reflects or describes illness experience but also contributes to the experience of symptoms and suffering. Kleinman (1988: 9) explains this by suggesting that ‘The meanings communicated by illness can amplify or dampen symptoms, exaggerate or lessen disability, impede or facilitate treatment.’ One study which illustrates the dynamic relationship between the person’s understanding of experience and how this experience develops was carried out by Escher et al. (2002) in the Netherlands. In this study, the researchers looked at children who had heard voices. At the beginning of the study these children were not considered to need input from mental health services, as the experiences were not of such a magnitude to indicate this. Over the next three years these children were followed up to see which, if any, might go on to meet ‘caseness’ (defined in their study as needing the care of mental health services). They found that the progression from hearing voices to needing mental health care input was associated with the child’s and parents’ appraisals of the voices rather than the voices themselves. That is, children or families who at the initial assessment had a more negative explanatory model for the voices, seeing them as more problematic and indicative of pathology, were, over the course of the next three years, much more likely to require input from mental health services. This study suggests that the understanding one adopts for an unusual experience (such as hearing a voice) may play a role in how this experience develops over time, and whether or not it progresses such that it causes levels of distress which indicate that mental health service input is required.

The degree to which psychotic experiences are distressing to the individual is an important though, at times, overlooked variable. This may reflect the assumption that psychotic experiences are inherently and inevitably distressing. However, research such as that by Romme and Escher (1989) in the Netherlands, demonstrates that this is not always the case. They found that significant numbers of voice-hearers have a neutral or even positive relationship with their voices and that the degree of distress associated with voices is related to the understanding that the person has of the experience, as opposed to being attributable only to factors inherent in the voice-hearing experience itself (such as the content of the voices). Those who understood their voices in a 'benevolent' framework (for example, seeing the voices as being a part of the self, or a guiding spirit) were less likely to report distress than those whose explanatory models were more 'malevolent' (for example, seeing the voices as being from a powerful negative source, such as the Devil). Research into voice-hearing in New Zealand found that those who understand their voices in a spiritual framework tend to be less distressed by the voices, and have less contact with mental health services than those who understand their voices in either biological or psychological terms (Beavan 2007).

Given that one of the primary goals of mental health services is to alleviate distress, it is clear that to achieve this goal clinicians must attend to the client's understandings of the experience. A common assumption held by mental health services is that the primary focus of treatment should be reducing symptoms. However, recent research has shown that the client's subjective appraisal of improvement (that is, feeling better) does not correlate with measures of symptoms, casting doubt upon the assumption that symptom relief is the main consideration for clients (Kupper and Tschacher 2008).

There is also research showing that one of the reasons that childhood trauma increases the risk of psychosis is that the previously traumatized group make negative attributions about and are therefore more distressed by their first experiences of hearing voices (Morrison et al. 2003). Other research which demonstrates the way in which one's explanatory model influences the actual experience include Birchwood et al.'s (1993) study which showed that those who view their experience of psychosis as an 'illness' (that is, those who accept the medical diagnosis) have higher rates of depression, and Fisher and Farina's (1979) research which found that people who view their psychotic experience in medical terms are less likely to develop and apply their own recovery strategies.

When considering the client's understanding of his or her experience, it is important to note that this does not exist in a vacuum; clinicians too have explanatory models for the client's difficulties. Client and clinician may, to varying degrees, have understandings which are congruent with each other, or which may be in conflict. For example, a New Zealand study of service users, most of whom received a diagnosis of psychosis, found that 69 per cent of those who had a history of being abused believed this was a causal factor in their mental health problems, but only 17 per cent thought their clinician believed this was the case (Lothian and Read 2002).

What are the clinical implications of the congruence, or lack thereof, between client and clinician explanatory models? Bannister (1985) investigated this very issue in relation to the psychotic experiences of patients in a British hospital. He found that congruence between the client and clinical staff on notions of the causes of psychotic breakdowns was associated with good outcomes for the client. He also found, however, that clinician–client agreement on what constitutes appropriate treatment bore no relation to the outcome. Based on these findings, Bannister (1985) warns of the risks of clinicians adopting a narrow biomedical perspective which may make it difficult for them to understand or appreciate the client's perspective and may blind the clinician to the personal significance of the experience and the client's wish or need to reflect on this experience. Some support for Bannister's argument can be found in the already mentioned Soteria House project, where good outcomes were found for clients who had had psychotic experiences (Mosher 2001). Staff exploration and validation of the clients' understandings were central to these successful outcomes. Within the recent British cognitive-behavioural approaches to psychosis, great emphasis is placed on clinician and client endeavouring to reach a joint understanding of the client's experience, which is seen as an important step in developing a helpful therapeutic relationship (see Bentall 2003; British Psychological Society 2000).

The research outlined above demonstrates that how one comes to think about and understand an experience has a significant role to play in a range of important variables, including the impact of the experience, how the experience develops over time, and how the individual responds to the experience as well as how the client and clinician relate in terms of looking at ways of dealing with the experience. Important considerations in the client–clinician relationship include how the client responds to advice from the clinician. This advice may include, for example, suggestions about medication and/or other ways of coping with psychosis. Medication is generally considered an important component of clinical treatment of psychosis, although there are well-documented reports that a significant proportion of clients do not follow medical advice regarding the use of anti-psychotic medications (Nosé et al. 2003). Budd et al. (1996) found that clients' beliefs are a good predictor of whether or not the client will comply with taking anti-psychotic medication. Of course, this is not at all surprising, as Helman (1981: 550) remarks 'Only if the prescribed treatments make sense to the patient will they be taken as directed.' This is consistent with advice given by Leventhal et al. (1992), who suggest that exploring the client's theory of illness can help shed light upon the reasons for non-compliance with medication, and as such, rather than being something which should be subject to further 'treatment' through 'adherence therapy' (Kemp et al. 1996) as is sometime suggested, non-compliance can be explored in an open and respectful way by clinicians, to help minimize potential conflict between the client and the clinical service. An interesting twist on the non-compliance literature is provided by Van Putten et al. (1976), who found that for a portion of in-patients who are non-compliant with anti-psychotic medications, this may reflect a conscious, deliberate choice showing a preference for the psychotic state over the 'treated' state. Here again we see potential for misunderstanding or even conflict between clinician and client if there is a failure to explore subjective aspects of the experience for the client, which may indicate that for some clients, at least some of the time, the psychotic state may actually be preferred to the medicated state.

Another important aspect of clinical work which has received considerable attention over recent years is in the use of coping strategies to deal with psychotic experiences (for example, Carr 1988; Falloon and Talbot 1981; Tarrier 2002). Research in this area shows, not at all surprisingly, that people who experience psychosis and find it troubling develop and utilize different ways of coping with the experience, with some coping strategies tending to be more effective than others. These findings have been adopted clinically, where clients are often instructed in the use of different coping strategies. However, such interventions commonly overlook an important finding from this research: clients do not develop or apply coping strategies randomly, but rather, the coping strategies they are willing to use are those which make sense *to the client* in terms of the client's own understanding of psychosis (Carr 1988; Falloon and Talbot 1981). Thus, clients' explanatory models have an important influence on which coping strategies will be applied, and clinical interventions aimed at teaching clients new coping strategies must also consider if and how such strategies fit within the clients' understandings. In the area of hearing voices, Romme and Escher (1993) note that if voices are seen by the individual as simply an 'illness', this tends to prevent any form of identification with the voices, which they see as a necessary condition for effective coping.

Attitude to and relationship with the psychotic experience

Closely related to, although not identical with, the way in which an individual understands his or her experience of madness, is the individual's attitude to, and relationship with the experience. This is an area of research which has made significant contributions to clinical practice in recent years. Central to this research are the twin concepts of 'sealing-over' and 'integration', which were first articulated by McGlashan et al. (1975). The recent revitalization of psychological approaches to psychosis has seen a resurgence of interest in these concepts. McGlashan and his co-workers use these terms to refer to the individual's attitude to and response to psychotic experiences. Those who 'seal over' tend to have fixed, usually negative views of their psychotic experiences, and may dismiss the experiences as having little or no personal significance; they put little effort into trying to develop a personal understanding of the experience, which is largely encapsulated and dismissed as irrelevant. By contrast, 'integrators' express interest and curiosity about the experience, which they see as having personal relevance, being somehow related to the ongoing patterns of their life and they look to learn about themselves from the experience of madness, seeing it as an opportunity to develop and grow. Integrators take a more open and flexible attitude to the experience, and are more likely to accept some personal responsibility, as well as seeing the experience as being linked to other life experiences such as stressful events, trauma, guilt etc., whereas 'sealers' do not see a relationship between the psychotic experiences and prior life problems, and may dismiss the whole experience as meaningless.

Though sealing-over and integration are sometimes discussed as if they were distinct ways of responding to psychosis, McGlashan et al. (1976) point out that they are best thought of as opposite ends of a continuum. McGlashan et al. (1976) show, through illustrative case studies, how the same individual can fluctuate between sealing-over and integrating. They suggest that factors influencing the stance an individual adopts include the response of significant others (including clinicians) and the use of medication, which may promote sealing-over. Larsen (2004) describes a small-scale study in Denmark looking at how clients relate to their experience and found that clients adopt both sealing-over and integration responses to their experience and which stance the individual adopts is related to the particular context within which he or she is discussing the experience: some ways of discussing the experience with the client are more likely to encourage an integrative response, whereas other ways of discussing the experience are more likely to engender a sealing-over response in the client.

Research into the relationship between client attitude to psychosis and outcome of the condition, though not conclusive, suggests that integrators fare better than those who seal over. McGlashan and Carpenter (1981) looked at in-patients with a diagnosis of schizophrenia and found some relationship between attitude to illness and outcome, with those who were less pessimistic about their experience tending to have better outcomes. Looking specifically at integration and sealing-over, McGlashan (1987) found that there was a tendency for integrators to have better outcomes. This finding was also evident, though less powerful, among those who had a diagnosis of schizophrenia. More recent research (Birchwood et al. 2000a, 2000b; Drayton et al. 1998) has found a clear relationship between attitude to psychosis and post-psychotic depression, with those who seal-over being far more at risk of depression in the post-psychotic period. Birchwood and his co-workers report that in their sample, all clients who became moderately to severely depressed following a psychotic episode had adopted a sealing-over response to their psychosis, with *none* of the integrators becoming depressed to this degree. This is quite persuasive evidence of the significance of client attitude to psychosis as being an important variable in course and outcome. Drayton et al. (1998) suggest that client attitude to psychosis and recovery styles may be related to early attachment experiences, such as trauma. This proposal found some support in another study which showed that 'sealer-overs' reported higher rates of childhood abuse from parents, suggesting that they may have lower psychological 'resilience' to deal with difficulties in later life, so leading them to seal over (Tait et al. 2004).

As McGlashan and others have pointed out, it is not only clients' attitudes to psychosis that can be conceptualized as reflecting a sealing-over versus an integrative approach: clinicians' understandings can also be considered along this continuum. Professional theories which emphasize biological factors would seem to fit more on the sealing-over end of this continuum, whereas those which locate the psychotic experience within the life experience of the client (such as psychodynamic, trauma-based and other psychological perspectives) are more integrative in their orientation. This may have some implications for the ways in which the client responds to the experience and also for how the client responds to treatment. One largely neglected study, with quite startling results, was reported by Whitehorn and Betz in 1960. They studied clinicians working in the USA with psychotic clients and found that the attitude held by the clinician towards the experience of psychosis was highly significant in influencing the outcome for the client. Clinicians who adopted a flexible, curious attitude to the client's inner world achieved positive outcomes for 75 per cent of their clients, which contrasted sharply with only 27 per cent positive outcomes being achieved where clinicians had dogmatic, inflexible, authoritarian approaches to the client's experience. The magnitude of this difference (75 per cent versus 27 per cent) is quite remarkable, comparing favourably with any difference found between interventions and control groups, including the use of anti-psychotic medications. Although this study is, inevitably, flawed in its methodology (with no clear control group, and measures of both clinician style and outcome in need of refinement), it is nonetheless disappointing that it has not led to further investigations to replicate or refute these findings. This research points to the role of the clinician's attitude to psychosis being a factor which may influence outcome for the client.

One model which may help us conceptualize the relationship between explanatory models and outcome for psychosis is proposed by Lafond (1998), who draws parallels between the normal process of grieving and response to mental illness. Lafond argues that it is crucial to consider how the person is responding to their experience, particularly for clients having their first psychotic episode, and that if the experience is properly processed by the individual (rather than being just dismissed), this may improve the outcome. Whether or not one accepts this particular model to conceptualize the research findings, it seems clear that client and clinician understandings of, and attitude to, psychotic experiences *do* have some impact on the course and outcome of the condition.

A persuasive personal perspective on this matter is provided by Rufus May (2002, 2003) who argues, from his own personal experience of psychosis and his clinical experience as a psychologist, that developing a personally meaningful explanatory model ('an enabling personal narrative') is a crucial part of recovery. He notes in passing that being diagnosed 'schizophrenic' was particularly unhelpful as it did not allow him to develop such a narrative. May is not alone in identifying the diagnosis of 'schizophrenia' as having a negative impact on the individual and being an obstacle to recovery over and above the experience itself. Reviewing studies of the disease model of mental illness, Mehta and Farina (1997) conclude that those adopting an illness model for mental distress report increased stigma from other people as well as increased self-stigma in the shape of a negative self-concept. Ritsher and Phelan's (2004) review of the literature in this area reaches a similar conclusion, noting that the process of internalizing negative stereotypes of mental illness is associated with demoralization, lowered self-esteem and unemployment. In their own study into psychotic patients, they found that internalized stigma is particularly common for this population, and that 'alienation' (the subjective experience of feeling not a full member of society, with 'spoiled identity') was a major component of this, and is associated with poorer outcomes and more depressive symptoms.

Warner (1994), reviewing empirical studies in this area, argues that those who accept a medical diagnosis of their condition may conform to the stereotype of incapacity and worthlessness, leading to poorer outcomes. Considering the now well-recognized, though poorly understood finding that in non-industrial societies those meeting criteria for a diagnosis of schizophrenia tend to have better outcomes than those who live in wealthier, more industrialized societies, Waxler (1979) proposes the possibility that this difference may relate to the different understandings of mental illness found in those societies.

May (2002) speaks about the importance of challenging the prevailing notion that mental health problems are to be seen only as 'disabilities'. He suggests that this can be done through seeing positives in the experience and recommends celebrating the uniqueness and resilience of those who have been through the mental health services. He refers to organizations in the UK, such as the Hearing Voices Network and Mad Pride, which are challenging cultural stereotypes by promoting a more positive perspective on the experience of mental health difficulties.

Most of the research into subjective aspects of psychosis that we have outlined so far has focused on how the individual understands and/or relates to the experience. These are, as we hope we have shown, important areas of research which can enhance our ways of making sense of madness. Another approach to investigating the subjective experience of psychosis is to consider how the individual describes the experience itself. Within mental health, and in particular within psychiatric diagnostic symptoms it is, as we shall see, common for assumptions to be made about the phenomenological nature of psychotic experience, and for these assumptions to be embodied in the names given to certain experiences (for example, 'thought disorder', which is, in fact, based on a description of disordered speech, and 'blunted affect', which is based on the individual *appearing* blunted). Now, the acid test of the accuracy of these assumptions and descriptions is, of course, the extent to which they correspond to the lived experience of the individual, given that it is this which they purport to describe. Research into subjective descriptions of the phenomenology of the experience by the individual can help draw attention to faulty assumptions about the nature of the experience and so can help us develop more accurate understandings and, potentially, more helpful treatments. We will illustrate this point by looking at research into negative symptoms of schizophrenia, although other features of psychosis (such as hearing voices, or delusional beliefs) can be, and indeed have been, subject to similar investigations which also shed further light on the nature of these experiences.

Phenomenological research – negative symptoms

The concept of 'negative symptoms' is a core component of current notions of schizophrenia, forming part of the DSM IV-R (American Psychiatric Association 2000) diagnostic criteria. Poverty of affect (or 'blunted affect') is a prime example of a negative symptom, considered a central feature of schizophrenia and, as the term implies, denotes a general lack of emotional responsiveness and emotional experience in the individual. This has now become a central tenet within the psychiatric literature, with countless research projects incorporating this concept. Our purpose here is not to provide an overview of this extensive research into negative symptoms, but to illustrate how research into the subjective experience of these negative symptoms can help us develop more accurate conceptualizations of what is actually going on.

When those who have been identified as suffering from 'blunted affect' are asked about what they are experiencing (Boker et al. 2000; Selton et al. 1998), we find that many report that they actually experience intense emotions (such as anxiety), despite appearing to others to be emotionally and cognitively dulled: that is, for some clients it may be that the paucity of emotion relates only to the expression of emotion, not to the actual emotional experience. As discussed more fully by Kring and Germans (2004), research of this sort shows that there can, at times, be a discrepancy between what observers may assume and what the individual is experiencing. This research draws our attention to an implicit, usually unstated assumption made within the psychiatric terminology, namely that expression of emotion (as noted by others) corresponds directly to the experience of emotion. This mistaken assumption reflects what Jenkins (2004) calls a 'failure of intersubjectivity': a failure to attend to the subjective experience of the other. There are clear clinical and research implications associated with this failure. Findings such as these point to the grave risks inherent in assuming that the internal state and experience of another can be gauged accurately and reliably by an outside observer without at least checking out these assumptions against the subjective reports of the individual. Here then, we have a prima facie case for the necessity of research into subjective experience if we hope to develop an adequate understanding of schizophrenia/madness, as well as helpful clinical services for those who have such experiences. In passing, it is worth noting that some (such as Healy 2002) have questioned whether or not the difficulties commonly considered to be negative symptoms of schizophrenia may, in fact, be attributable to side-effects of neuroleptic medications, being part of a 'neuroleptic-induced deficiency syndrome'.

Conclusions

Our intention in this chapter was to substantiate our claim that to develop an understanding of madness, we need to recognize, acknowledge and incorporate subjective aspects of the experience (which, by definition, are only accessible to those who have the experience) into our understandings. Unfortunately, as we have shown, this is a much neglected area as far as scientific research into madness is concerned, and an inevitable consequence of this neglect is that our conceptualizations as well as our clinical treatments are diminished. Remedying this situation will require a change of attitude, such that those who have experienced psychosis are recognized as experienced-based experts who can make valid and valuable contributions to our understandings of psychosis. Adopting such a position may require us to develop new ways of thinking about what we mean by madness/schizophrenia/psychosis. In Chapter 6 we outline our framework, which developed out of our own research in this area, and which we believe provides a way of thinking about madness which allows for, indeed assumes, that a multiplicity of perspectives be brought to bear on the complex set of experiences that we refer to as madness. In addition, new methods of doing research, which are more appropriate to investigating such elusive areas as phenomenology, personal understanding, and the meaning of experience and which compliment rather than replace traditional methods, will need to be developed and utilized in order for such research to be done. In Chapter 3, we will discuss our own research into the subjective experience of psychosis which illustrates one way in which such research might be carried out.