



PERGAMON

Social Science & Medicine 56 (2003) 299–312

SOCIAL
SCIENCE
&
MEDICINE

www.elsevier.com/locate/socscimed

Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals

Beate Schulze*, Matthias C. Angermeyer

University of Leipzig, Department of Psychiatry, Johannisallee 20, 04317 Leipzig, Germany

Abstract

Schizophrenia has been found to be one of the most stigmatising conditions. To the present, most research on stigma related to mental illness has drawn conclusions on the adverse reactions faced by people with schizophrenia from studies on public attitudes or analogue behavioural studies. The views of those exposed to the stigmatising reactions, however, has largely been absent. Aiming to explore stigma from the subjective perspective of people with schizophrenia, a focus group study was carried out at the four centres involved in the WPA Global Programme against Stigma and Discrimination because of Schizophrenia in Germany. In order to get a comprehensive picture of how stigma affects the lives of schizophrenic patients, collateral information was sought from relatives and mental health professionals. The focus groups enquired about concrete stigmatisation experiences of the patients and incidences of stigma witnessed by the other two groups. Focus group sessions were tape-recorded and transcripts were coded using an inductive method. Results reveal four dimensions of stigma: interpersonal interaction, structural discrimination, public images of mental illness and access to social roles. Examples are given for the views of patients, relatives and mental health professionals on each of the four stigma types. The consequences for conceptualisations of stigma and the development of effective strategies to reduce stigma and discrimination because of schizophrenia are discussed. © 2002 Elsevier Science Ltd. All rights reserved.

Keywords: Stigma; Discrimination; Schizophrenia; Germany

Introduction

The experience of schizophrenia is not limited to the symptoms of the illness. It is accompanied by what Finzen (1996) calls a “second illness”: the reactions of the social environment, the stigma associated with the disorder. Stigmatisation is a dimension of suffering added to the illness experience, and has been found to lead to social isolation, limited life chances and delayed help-seeking behaviour (Link 1982, 1987; Fink & Tasman, 1992; Rosenfield, 1997; Angermeyer, Matschinger, & Riedel-Heller, 1999; Sirey, Bruce, Raue, Perlick, Alexopoulos, & Meyers, 1999). Of all mental illnesses, schizophrenia appears to be the most stigma-

tised disorder. While depression, anxiety disorders and eating disorders have seen an increasing public interest, schizophrenia remains associated with negative stereotypes such as violence and dangerousness (Angermeyer & Schulze, 2001).

In his seminal work on stigma, Erving Goffman (1986) conceptualises stigma as an “...attribute that is deeply discrediting...” and makes the person carrying it “...different from others and of a less desirable kind” (p. 3). An awareness of the attribute then results in the belief that “...a person with a stigma is not quite human” (p. 5). Stigma, then, affects the very identity of those the negative attribute is ascribed to, and complicates interaction situations with those who Goffman calls “the normals” (p. 13).

In the process of stigmatisation, human differences such as having a mental illness are distinguished and

*Corresponding author. Fax: +49-341-97-24-539.

E-mail address: BeateMSchulze@web.de (B. Schulze).

labelled. According to Lemert (1951) "...the formal ascription of a deviating characteristic" (p. 12) by means of a label sets off the process of "formal social stigmatisation" following a deviation from social norms. Labelling thus is seen as the prerequisite for the very existence of deviance that could justify stigmatisation. As Becker (1963) points out: "The person with deviant behaviour is a person to whom this label has been successfully applied; deviant behaviour is behaviour that has been labelled as such by others" (p. 9). In line with prevailing cultural beliefs about a condition, labelled persons are then linked to undesirable characteristics. These negative stereotypes serve to justify the separation of those whose status is imbued with negative meanings from others: they are placed in distinct categories which is accompanied by status loss and discrimination. (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Link & Phelan, 2001).

Research on stigma has attempted to throw light on the various components of this process. Much of our knowledge on stigma has been informed by *studies on attitudes and beliefs* about mental illness among the public. Attitude surveys have illustrated the type of characteristics associated with schizophrenia (Angermeyer & Matschinger, 1995a), general attitudes about mental illness (Nunnally, 1961; Taylor & Dear, 1981; Huxley, 1993; Wolff, 1997) and self-reports of population samples on social distance questions (Angermeyer & Matschinger, 1995b). Research on public attitudes has produced a negative picture: people with schizophrenia are perceived to be unpredictable, aggressive, dangerous, unreasonable, little intelligent, lacking in self-control and frightening (Angermeyer & Matschinger, 1995a), and a large share of the general population would reject entering particular social relationships such as sharing a flat with someone with schizophrenia, recommending a person with schizophrenia for a job or having him/her look after their children (Angermeyer & Matschinger, 1995b). Recent studies have shown that large-scale public education campaigns on mental illness and the increasing integration of psychiatric services in the community have done little to alter the stigma associated with mental disorders (Phelan, Link, Stueve, & Pescolido, 1997; Phelan & Link, 1998). The results of attitude surveys are then used to draw conclusions on the negative reactions people suffering from mental illness are exposed to. However, this connection is problematic as research on public attitudes does not provide information on the relationship between attitudes held by the public and their actual behaviour if they came in contact with someone suffering from schizophrenia.

A second research tradition in investigating the stigma of mental illness are *analogue behavioural experiments*. These studies actually measure stigmatising behaviour by making subjects believe they are interacting with

someone suffering from mental illness and recording their reactions. Analogue behaviour studies have shown that a fictional mental illness status conferred upon subjects led to more negative ratings of their test performances and stigmatising perceptions in the absence of any unusual behaviour (e.g. Farina & Ring, 1965; Piner & Kahle, 1984). Experimental studies further revealed that if a person mentioned a mental health problem, s/he faced greater difficulty in finding job, renting an apartment or being accepted in a neighbourhood than in the control condition (e.g. Farina & Felner, 1973; Farina, Thaw, Lovern, & Mangone, 1974; Page, 1977). Whereas experiments have documented actual behaviour, they have done so in laboratory conditions. Thus they are only of limited value when we seek knowledge on the stigmatising reactions people with mental illness experience in real life situations.

While there is a wealth of research on stigma and discrimination because of mental illness, the way patients experience the adverse reactions by others emerging from attitude research and analogue experiments has largely been neglected. In addition, stigma research in general has been challenged for drawing on theories and concepts that are uninformed by the lived experience of the people studied (Link and Phelan, 2001). In response to this deficit, attempts have been made to take account of the perspective of those receiving stigmatisation.

The words and perceptions of people with mental illness were first given room in the scientific discourse of psychiatry when some journals (e.g. *Schizophrenia Bulletin* or *Psychiatric Services*) started publishing first-person accounts of mental illness. Experiences of stigma and discrimination such as being avoided or treated as less competent by others are a frequent topic in these statements. Despite providing valuable insights, first-person accounts are highly selective as the awareness of this opportunity to report on one's situation and the standards of writing required for publication limit the access to this forum to those suffering from less severe conditions and to people with a high level of education and social competence.

A further approach taking account of the patients' view on stigma is the Perceived Stigma Scale developed by Link, Cullen, Frank, and Wozniak (1987). Based on the assumption that individuals acquire conceptions of what it means to be mentally ill in the course of their socialisation, the scale measures the extent to which psychiatric patients believe that others ("most people") will devalue them and discriminate against them. Further to assessing whether those with mental illness are aware of the presence of negative attitudes in the population, Link, Cullen, Struening, and Shrout (1989) investigated patients' responses to their stigmatised status. Here, they found that those who perceived more

devaluation and discrimination on the part of the public towards the mentally ill were more likely to apply strategies such as secrecy and withdrawal in order to avoid negative reactions. This approach was the first to enquire the patients' view of stigma. However, it still does not provide information on concrete incidences of stigma experienced by those suffering from mental illnesses.

One study which has examined the extent to which people with mental health problems encounter stigma in their daily lives is that of Wahl (1999). Developing a questionnaire based on stigmatisation experiences commonly reported in personal accounts of mental illness, Wahl questioned 1,301 mental health consumers from across the US and Canada. Respondents reported having witnessed stigmatising comments or depictions of mental illness, having been treated as less competent by others once their illness was known, being shunned or avoided, and being advised to lower their expectations in life. However, results are limited in terms of generalisability as the distribution of the questionnaire was connected to the National Association of the Mentally Ill (NAMI), thus addressing only those people with mental illness involved in an advocacy organisation. As a consequence, the sample consisted of relatively high-functioning individuals, and was self-selected. People with schizophrenia, i.e. those most likely to face stigmatising reactions, are underrepresented.

The present study explicitly addresses the stigma associated with schizophrenia. We sought to find out the concrete situations in which those living with a potentially stigmatising condition feel that they are "disqualified from full social acceptance" (Goffman, 1986, p. 1), and how the stigma affects their everyday lives. We sought to obtain additional information from those in close contact with the patients: their relatives and mental health professionals. In contrast to previous studies on the subject which were based on questionnaires drawing on social theories of stigma or on the statements of a very selective group of people with mental illness, our research aims at exploring the concepts with which the "recipients" of stigma think about their situation.

Method

Rationale

Qualitative research methods are particularly suited for exploring subjective views on an issue. They put the subject and its perception of the world at the centre of their attention. The lived experiences of those studied or their accounts of it serve as the basis for data analysis (cf. Flick, v. Kardorff, Keupp, v. Rosenstiel, & Wolff, 1995). In addition to generating a typology of stigma-

tisation experiences, a qualitative approach allows to illustrate what particular types of stigma mean to the patients and to document different foci in the perception of stigma between the three groups questioned. With this in mind, stigma experiences were explored in focus groups with schizophrenic patients, their relatives, and mental health professionals.

Focus groups are commonly used as a form of qualitative research method in the sociology of health and illness (e.g. Conrad, 1990; Roche, Guray, & Saunders, 1991; Wakefield, Reid, Roberts, Mullins, & Gillies, 1998; Lawton & Parker, 1999). Compared with individual interviews, focus groups allow access to research participants who may find one-on-one, face-to-face interaction intimidating (Morgan, 1988). This may be particularly true for people with schizophrenia who may be reminded of therapeutic relationships in an interview situation and thus adjust their communication to this familiar interaction setting, expecting to get help through an expert's knowledge and advice. Our study seeks to place those who experience stigma and discrimination in their everyday lives in the role of experts whose knowledge and experience is essential to advancing the theoretical discussion on stigma. In addition, focus groups create multiple lines of communication and thus offer participants a safe environment where they can share experiences, ideas and beliefs in the company of people which have a central element of their experience in common. The resulting atmosphere of familiarity is helpful in facilitating statements on difficult, unpleasant subjects such as stigma (cf. Steward & Shamdasani, 1994). Moreover, the interaction among group participants often reduces the amount of interaction between the moderator and the individual members of the group. In this way, the dynamics within the group decrease the influence of the researcher over the interview process and hence give a more prominent role to the participants' opinion (Madriz, 2000). In addition, the group setting has a synergistic effect: the group dynamics stimulate thinking and verbal contributions. Less direct methods such as focus groups are also considered as more appropriate to elicit responses that better reflect the social realities of the interviewees (Krüger, 1994). With particular reference to our research objective to explore concrete stigmatisation experiences in order to incorporate the lived experiences of those experiencing the stigma into understanding the stigma process and its effects, focus groups were chosen as the appropriate method for obtaining the information we sought.

Focus group participants

In the context of the WPA-Programme against stigma and discrimination because of schizophrenia, a focus group study was carried out at the four German centres

involved in this programme (Munich, Leipzig, Düsseldorf und Kiel/Hamburg/Itzehoe). For our study, 12 focus groups were conducted: one with people suffering from schizophrenia, one with their relatives and one with mental health professionals at each of the four centres. In total, 83 individuals participated in the group discussions: 25 patients, 31 relatives and 27 mental health professionals. 64% of the sample were female, 36% were male. Participants were recruited through letters of invitation which were distributed through the centres' out-patient departments and office-based psychiatrists, the regional boards of the Federal Association of Relatives in Germany (BApK) and through the local co-ordinators of the anti-stigma programme at the respective psychiatric hospitals. The selection of the addressees for the invitations was based on the following criteria: Patients were selected when they had an ICD-10 diagnosis of schizophrenia and were in out-patient treatment at the time of the focus group session. This criterion was motivated by the fact that group participants should currently be exposed to everyday life situations and community reactions and that they were not experiencing an acute psychotic episode. Relatives were contacted when their family member had a diagnosis of schizophrenia. Mental health professionals were selected in such a way that the different professional groups working in the mental health sector (psychiatrists, psychologists, social workers, occupational therapists and nurses) were equally represented in the focus groups. The focus groups addressed three issues: concrete stigmatisation experiences, ideas about the causes of stigmatisation and suggestions for anti-stigma interventions. The present article focuses on the stigmatisation experiences.

Focus group sessions

Focus groups are group discussions with 8–12 participants. The moderator addresses a number of

issues (foci) for discussion and assures that the discussion remains on the subject of interest. Apart from this function, interference with the discussion is kept to a minimum, which is motivated by the aim to create a communication situation which bears close resemblance to “naturally occurring interaction” (Morgan, 1997). In the present study, group participants were asked to discuss what had changed in their lives after they first developed schizophrenia. A set of focus group guidelines was developed for the moderator which included probes designed to re-focus the discussion if necessary (see Table 1). After those who had followed the invitation had consented to participate and agreed to the recording of the session, discussions lasted approximately 2 h.

In the focus groups with relatives and mental health professionals, collateral information was sought on how these two groups with whom people with schizophrenia maintain the closest social relationships view the situation of the patients.

Analysis

Focus group discussions were tape- and video-recorded and transcribed. Video tapes were used to assist the transcription of group data. The full set of transcripts was then analysed by means of inductive formation of categories from the texts, aiming at establishing a typology of stigmatisation experiences from the spoken words of the focus group participants (Huberman & Miles, 1994). Coding was assisted by WinMax (Kuckartz, 1988, 1998), a computer programme for qualitative data analysis. The programme allows simultaneous access to the texts analysed, the coded blocks of text and the categories of the coding system relevant for the respective transcripts.

Code mapping was carried out in line with the method suggested by Knodel (1993). Transcripts were analysed separately for the three different areas covered in the focus groups (stigma experiences, stigma causes and

Table 1

Focus group guidelines for exploring the stigmatisation experiences of people with schizophrenia

STIGMATISATION EXPERIENCES

Opening question:

What has changed for you after you first developed schizophrenia? Tell me *concrete incidences and stories* that you experienced!

[if nec., probe: work, family, friends, education, everyday life]

Further questions (alternative):

Were there situations in which you felt excluded or misunderstood?

[if nec., probe: when? where? can you describe? other situations than you already described?]

Did you tell other people that you had schizophrenia?

[if nec., probe: whom? when? why? why not?]

How did people around you react when they found out you had schizophrenia?

[if nec., probe: withdrawal, interest, gossip, support?]

suggestions for projects aimed at reducing stigma). Starting from the material, relevant blocks of text were chosen with regard to the research question, i.e. the search for a pattern experiences discussed in the groups. All relevant blocks of text were given a code reflecting the original statement as closely as possible (paraphrasing). Paraphrases then served as the basis for category formation. The coding system thus constructed was constantly revised in the course of the analysis. Categories with similar content were summarised. If further paraphrases occurred in the course of analysis, they were added to the coding scheme. At the outset of analysis, transcripts were coded simultaneously by two researchers. The coding systems arrived at were compared and the allocation of blocks of text to particular categories was discussed in the team. Discussions were supervised by two further researchers with substantial experience in qualitative data analysis. Through this complex process, the final coding system was developed. Subsequently, stigmatisation experiences were summarised in generic categories according to their type and the area in which they were encountered. The focus groups with relatives and mental health professionals served as an additional perspectives on the patients' experiences. Thus, transcripts for these groups were coded deductively, using the coding system developed from the patients' experiences as a reference. Coding was open to include new stigma dimensions should they become evident from the statements of the collaterals. In line with Silverman's (2000) argument, coding was used as a way to organise the data in patterns which then served as a basis for analysis and interpretation. In addition, instances in the final categories were aggregated with the aim of documenting the relative incidence of the different codes and thus weighting the importance of the individual categories (Coffey & Atkinson, 1996).

Results

Dimensions of Stigma

From the statements of the focus group participants, we identified four dimensions of stigma: interpersonal interaction, the public image of mental illness, structural discrimination, and access to social roles.

Interpersonal interaction

The first dimension, interpersonal interaction, refers to stigma and discrimination experienced in the context of social relationships. For most patients, the diagnosis of schizophrenia resulted in a *reduction of social contacts*. C., a woman who has been suffering from schizophrenia for 15 years, describes the reaction of her neighbours to her second psychotic episode:

"And then I told my neighbour that I had to go back to hospital and asked whether she could do the stairs for me again when it's my turn, and then she said: 'What a pity about your flat!' and slammed the door in my face. I was totally puzzled... and the relationship with the neighbours changed completely. I mean, I remember how well we got on together for decades, how we went on holidays together, how we talked to each other, how we treated one another. That had been totally different before... and (this realisation) hurt me so much."

Patients agreed in stating that those not affected by mental illness have little understanding for the behaviour of people with schizophrenia and the difficulties they are faced with. Instead, patients were often ignored by neighbours and family members.

Relatives, too, observed how friends of the patients gradually stayed away, did not come to see them at the hospital, or that they shied away from speaking with them as there was "*nothing to talk about with [them]*". One father recounts the explanation of his son's friend for his staying away: "*He is just talking incomprehensible rubbish anyway. I'm out of here!*" In the relatives' view, patients were finally left with "*inferior contacts*": people they meet in psychiatric settings. "*And then there's only one topic: the illness.*", as K. whose daughter suffers from schizophrenia states.

The patients participating in the focus groups further expressed that there was *little interest in information about schizophrenia* on the part of their friends and relatives. According to those questioned, schizophrenia is not recognised as an illness by the lay public. On the other hand, as soon as contact with psychiatry became known to their social environment, most people with schizophrenia faced negative reactions, such as the reduction of their person to "*being crazy, irresponsible for one's actions, being someone who cannot be trusted*". They were increasingly carefully watched over, and every somewhat conspicuous detail was ascribed to the illness. Further, there was agreement among the patients that one single contact with psychiatry was sufficient to put a life-long stamp on them, a stigma, which, in turn, *determined their social identity* in various interaction situation they entered. G., who has suffered from episodes of schizophrenia compares this to

"being in some sort of invisible cage... What bothers me is that my ambition is being restrained. They are trying to force me into some sort of a cliché, and they don't leave me any possibility for development."

Moderator: "Who? Everyone around you, people at work, your friends?"

G.: "I don't have any friends. My mother is trying to hamper that, the doctors said that I shouldn't bother

studying, I mean, continuing my studies and... I would really like to work as a programmer, but they tell me that isn't possible, because with that illness, I wouldn't be capable for that. That's what bothers me, you know!"

An important consequence of the stigmatisation encountered by schizophrenic patients in the context of social relationships is *secrecy*. Patients experience their contact with psychiatry as a "*stain on one's reputation*" and wish to conceal it even from friends and relatives, often as a consequence of previous negative experiences. Mental health professional confirm that strategies to hide the illness from others are a frequent topic in their consultations. They observe a desire to maintain "normal life" which patients see compromised by psychiatric treatment. A social worker recounts the following experience from his daily practice:

"Only this morning I talked to a patient about this. In the beginning of his illness, he had the feeling that he should be very open about the mental illness, that he should confront people with it, at least his friends and relatives, but now he's taken the decision that he'd rather not tell anyone. He says that when he openly speaks about the illness, he's not taken seriously anymore, that when something he does deviates only a tiny bit from normality, people immediately say... 'Oh, well, he's mentally ill anyway'."

Respondents further reported concrete incidences of *discrimination*. For example, people with schizophrenia experienced difficulties with landlords up to the point of being evicted when the illness came to light. In some cases, they were accused of misconduct and criminal behaviour. Patients described that they often serve as "scapegoats" and are the first to be held responsible for problems occurring in their environment.

Exclusion and discrimination did not only occur in the context of social relationships with friends, relatives and neighbours, but also *in the contact with mental health professionals*. In their relationship with mental health professionals, patients felt stigmatised by a lack of interest in their person and the history of their mental health problem. They express a general feeling that there is only one standard psychiatric treatment for everyone, mainly consisting in "*experimenting with the type and dosage of drugs*". As E. who has been living with schizophrenia for 5 years recounts:

And when you get to the hospital, the first thing is sedation. Nobody is talking to you. You have no idea what is going on. And then all patients get the same drug, no matter what's the history of their problem, and it's only after a few days that a patient is asked what is actually wrong with him.

Focus group participants further criticised that a psychiatric diagnosis is often given with a negative prognosis such as "You've got schizophrenia, you will be ill for the rest of your life" or "Your illness means that you will end up committing suicide". In addition, it was noted that, during in-patient treatment, patients did not get the personal attention they needed. K., whose daughter is living with schizophrenia, puts it as follows:

"Whenever we came to see our daughter at the hospital, other patients come to her room and congregated around us, craving for personal contacts with someone other than their fellow-patients. Doctors and nursing staff should really take care of that need rather than sticking to work to rule!"

Often, patients felt that their needs and perspectives were not taken seriously. This was particularly true when those with schizophrenia were receiving *treatment for somatic problems*. On such occasions, the knowledge of a history of psychiatric treatment resulted in the situation that physical complaints were taken less seriously or that doctors immediately considered transferring those patients to the psychiatric unit. This experience is confirmed by the mental health professionals. As part of their daily work, psychiatrists regularly found that their patients were confronted with negative reactions on the part of colleagues from other disciplines. Schizophrenic patients referred for a specialist consultation as part of their in-patient treatment reported that they were treated with disrespect in other departments of the hospital, having to wait for longer than other patients, being ridiculed, or facing the suspicion that their physical complaints may only be imaginary. B., a nurse at a psychiatric day hospital reports:

"It is the case that our patients have to wait much longer in certain departments at the university hospital, and the way of speaking to them is often really condescending. They often hear things like "Oh no, not one of them again!" ... In some departments it's so bad that patients have said 'I won't go back there!'"

A further factor related to the treatment of schizophrenia which is experienced as stigmatising and as having a negative impact on the patients' social relationships are *medication side effects*, such as extrapyramidal symptoms and weight gain. These visible signs of the illness (or of the fact that one receives psychiatric treatment) connect the person displaying them with the negative stereotypes associated with mental illness. Patients described that this led them to avoid social contacts as they were no longer capable of concealing the illness, and thus dissolved what was perceived as protection against a priori devaluation in interaction

situations. In addition, side effects adversely affected the self-esteem of those suffering from schizophrenia, which further complicated interaction with their social environment and efforts to establish new social contacts as a large share of previous social network ties had been dissolved.

Public images of mental illness

People with schizophrenia and their families are well aware of the stereotypes about mental illness held by the public and disseminated by the media, in feature films and in advertising. The dominance of negative images about schizophrenia is not merely perceived as a cause of stigma and discrimination, but rather experienced as directly discriminating and hurtful: it is an integral part of the stigmatisation experience.

According to all three groups participating in the focus groups, the public image of mental illness is dominated by the view that people suffering from mental illness (and schizophrenia in particular) are *violent and dangerous*. Those questioned state that the media are responsible for disseminating this view. Newspapers, TV broadcasts and feature films are cited as the main source of information about mental illness for the public. As one patient states: “*They get their knowledge from BILD [the largest German tabloid] or from TV...*”. The kind of information offered is bound to cast a negative light on those with a mental disorder: Those suffering from schizophrenia are particularly concerned about the fact that media portrayals of mental illness almost exclusively take place in the context of court and police reporting. Accounts of particularly horrific, apparently unmotivated crimes use the mental illness as an explanation for the seemingly unexplainable. G., a woman who has recently had her first episode of schizophrenia says that, as a result of this type of reporting “*... all they know is that someone with schizophrenia set off a hand grenade in a church on Christmas Eve.*”

In addition, patients perceive the negative media reports as an *indication for a hostile social climate* towards people with schizophrenia—an awareness which induces them to avoid social contacts out of the fear to face rejection. The following sequence from a discussion on this issue among two people suffering from schizophrenia illustrates this point:

B.: “Where does this image come from? Well, in my opinion, that’s relatively clear. It’s because whenever a child is killed somewhere, or someone is raped and so on, they say that the perpetrator is mentally ill, and he’s been sent to the closed ward, etc.”

D.: “...at the psychiatric hospital.”

B.: “And, well, there’s always this connection... that people like us [my emphasis] do these things once in a while....”

The mental health professionals participating in the focus groups are concerned that patients initially hold the same stereotypes as the rest of the population as they, too, receive their knowledge on mental health issues mainly from the selective accounts of the media. As a consequence, patients are confused by their knowledge of schizophrenia and are less prepared to accept a psychiatric diagnosis which limits the chances for a successful psychiatric treatment. One psychiatrist reports from her daily practise:

“Or what you see in crime series on tv. It seems there is a particular trend at the moment. Nearly every week, one of the perpetrators portrayed in these films ends up in a psychiatric hospital, because he’s committed a horrific crime. And this shapes the public image, also among the patients. They’re afraid they might find themselves attacking someone one day, and they’d rather not stay at the hospital because they’re scared of the other patients.”

A second central constituent of this dimension of stigma is that *the public does not differentiate between mental illness and mental retardation*. “*People think that we’re stupid*”, says a woman who has schizophrenia. For the patients taking part in the discussion, the diagnosis of schizophrenia implied that they were considered incompetent, irresponsible for their actions and equipped with below-average intelligence. Facing such reactions made them feel devalued and lowered their self-esteem, they state.

The *public view of psychiatric treatment* is described as further adding to the stigma experienced by people with schizophrenia. Although psychiatric treatment has changed dramatically with the introduction of psychotropic medication and community care, participants in the focus groups state that psychiatry continues to be associated with the “loony bin”, the large-scale mental hospital. L., who has had schizophrenia since he was 19, expresses this as follows:

“Well, when people hear psychiatry, they immediately think of the ‘loony bin’. It’s like what you can see in the movies: Barred windows, people are tied to their beds, and what have you. There is a strict order of the day, and you can tell by the looks of people walking around there that they are having problems.”

As a consequence, coercive treatment and custodial care appear to be the adequate way of dealing with people with schizophrenia in the eyes of the public. Through the stereotypical view of psychiatry, the patients questioned perceive themselves as being

stigmatised indirectly: those who require such treatment must have a terrible problem and should better be avoided, or even “locked up”.

The *separation of mental illness from physical illness in the public discourse* is seen as a further sign of the exclusion of mental disorders from general debates on health and illness. Patients, relatives and mental health professionals alike complain about the fact that there is hardly any information and advice available for mental illness while public information campaigns and support services are organised for somatic disorders such as diabetes or HIV. The same is true for media reports: somatic illnesses are discussed on the health pages, experts are interviewed on the topic, there are specific health magazines, but mental health problems are largely excluded from this discourse. Especially from the relatives’ point of view, the availability of information is perceived as an indicator of the status of mental illness in comparison with physical illness. As B., whose son has had schizophrenia, exclaims:

“Just look how often and in what sort of magazines you can read something about Cholesterol, for instance. Even in the tabloid press, and so often that you’re getting sick and tired of it! And when you want to know something about a mental disorder, you only hear about it when a patient has committed a crime, and that’s all. And this is a really big mistake!”

As a result of the public perception that mental illness “*is not a real illness*”, focus group participants find that recurrent mental health problems are hardly tolerated, while regular visits to a physician for a physical complaint are accepted as perfectly normal. C., psychiatrist at a day hospital, illustrates this point as follows:

“Well, I always think that people have this idea in their heads that having psychological problems is OK, but only once in a lifetime. If that happens more often, something must be seriously wrong. But it’s totally different with an internist, for example. There are chronic illnesses where you regularly have to see an internist, and no one would be reproached for going to an internist for the fifth or sixth time because of a rheumatoid arthritis. If you have a psychosis and see a psychiatrist for the fifth time, on the other hand, then it is immediately concluded that you’re beyond help!”

Those questioned further observe a differentiation among different types of mental illness concerning the kind of information available to the public. Here, they state, depression and anxiety disorders have recently received more positive public attention and are becoming increasingly accepted, while schizophrenia remains associated with unpredictable behaviour and personal

failure rather than being considered as an illness: “*Even princes allow themselves the odd depression, but schizophrenia, this means crazy, mad*”, as one patient puts it.

Media accounts associating people with schizophrenia with violence and dangerousness are perceived as particularly harmful as they foster *public resistance against mental health care facilities* in residential areas, thus depriving those suffering from schizophrenia of adequate treatment and rehabilitation facilities. E., whose son has been living with schizophrenia for 15 years recalls her experience:

“We [the relatives’ association] want to build this housing project, with our own money. The problem is that we live in one of the most beautiful residential areas, a very posh neighbourhood. There are a lot of celebrities living there, only rich people, all millionaires. And they founded a citizens’ initiative, put posters up everywhere saying: ‘Psychiatry in our neighbourhood—never!’. And one of these famous folks, the president of a very popular football club, said at one of their meetings: “Nobody will build a madhouse in our area! And I will personally take care of that!”

Structural discrimination

The third dimension of stigma shows that stigma because of schizophrenia reaches beyond the realm of direct social interaction. Stigma and discrimination are also experienced through imbalances and injustices inherent in social structures, political decisions and legal regulations. The *poor quality of mental health services* is perceived as the strongest form of structural discrimination. Patients experience a lack of community-based services. They highlight a particular need for out-patient services and a focus on prevention rather than acute psychiatric care. Adequate psychiatric treatment, the patients participating in the focus groups state, should involve a comprehensive plan for treatment and rehabilitation, taking account of the difficulties schizophrenic patients face outside the hospital, in their everyday lives. They stress the necessity of networking between in-patient treatment, after-care and reintegration services (e.g. job centres and social services). Patients further complain about a lack of information about the treatment and about support services available in the community. In agreement with the patients’ description of the situation, relatives highlight the need for an improved treatment for those with schizophrenia as a central step in counteracting the stigma they face. In particular, relatives feel that patients often do not receive *adequate help in crisis situations*. Here, they state that access to in-patients crisis intervention is increasingly limited due to the strict legal regulations for involuntary commitment, and that they often feel

incapable of protecting the patient in times of acute crisis. Support services for such situations are felt to be missing.

Deficits in the quality of care provided are seen as resulting from an *inequitable distribution of resources in the health care system*. According to those questioned, mental health services are disadvantaged in discussions about health care expenditure. They feel that the financial means allocated to psychiatric services are very restricted and designated to a limited range of services: namely psychotropic drug treatment and organic diagnostic procedures. As K., two of whose daughters suffer from schizophrenia observes: “*CT is simply carried out, nobody would question its necessity and wonder where the money for it should come from.*” On the other hand, receiving *health insurance coverage* for services specially designed for people with mental health problems such as specific forms of psychotherapy and mental health care in the community is described as being exceedingly difficult. As a result, relatives wanting their ill family member to benefit from optimal treatment services are faced with a considerable financial burden. Those working in the mental health field face tough negotiations with insurers, who often do not perceive those with mental health problems as their clientele because the services these patients require go beyond the standard medical treatment. As one psychiatric nurse recounts:

“It is immensely difficult to get any funding for the psychiatric nursing service we operate. We basically can’t get any money. It’s only through a kind of misleading packaging that we can maintain our services. It’s like that: we are not actually registered as a psychiatric nursing service, but we operate as a somatic one. There’s no such thing as psychiatric nursing within the criteria of the private nursing insurance, and often we cannot justify the amount of time we spent with the patients, the time we need to even build up a trusting relationship. Sometimes we just can’t afford meeting the needs of our patients, ‘cos we aren’t getting paid for it.”

In the eyes of the patients, *value orientations in society* such as achievement-orientation and competitiveness are seen as contributing further to the stigmatisation of people with schizophrenia. Through a general focus on economic success, flexibility and activity, people suffering from mental illness are hardly capable of meeting the dominant criteria for social recognition and integration. M., who suffers from psychosis describes society as

“...a competition between the crazy ones and the normals.... This is an endless game of who asserts oneself over whom, who wins this game. The mentally ill are more sensitive and react more strongly to pressure, and thus they lose this game.

It’s a vicious circle. We can’t get out of it. It all depends on who’s the first to crack up.”

The high demands on performance and the view that people with mental illness are not capable of fulfilling them have a particularly negative effect on their situation on the labour market. As A., mother of a son suffering from schizophrenia exclaims:

“You see, now we get to the point: in our society, among the public, what is it that counts? Achievement, Turnover, Profit!!! And psychiatry, I mean the patients, they can’t keep up with that.”

Access to social roles

The stigma of schizophrenia also expresses itself in the situation that the illness represents a major obstacle denying access to important social roles. Most frequently, it was stated that the illness imposes barriers on *access to employment* and related professional roles. For the patients, returning to one’s job after a period of psychiatric treatment was often accompanied by critical remarks, mistrust and the denial of skills previously proven. Comments such as “*Without you things were running more smoothly.*” are not a rare occurrence. Under such circumstances, people with schizophrenia feel that they are the first to lose their job.

The employment situation of people suffering from schizophrenia is further complicated by the dilemma as to whether or not to reveal the illness to potential employers. Honest information about a history of psychiatric treatment in application forms or job interviews results in the fact that employment does not come about in the first place, while wrong information or concealing the illness involves the danger to be dismissed due to the concealment in case the truth comes to light. Regardless of this risk, patients recommended to keep the illness to oneself and explain periods of prolonged absence with fictional diagnoses such as “*metabolic disturbance*” or “*exhaustion syndrome*”. Mental health professionals confirm that their patients ask for “*fake diagnoses*” and for the use of “*neutral*” hospital stamps on sick notes in an attempt to conceal the illness. They further describe that patients ask their advice as to how to explain prolonged periods of joblessness on their CV caused by recurrent psychotic episodes.

Asked the question as to whether his current employer knows that he has schizophrenia, F. who has been suffering from schizophrenia describes the situation as follows:

“No, he doesn’t, and I wouldn’t recommend to anyone talking about the mental illness in work at all! I mean, you can talk about... well, perhaps a depression or something... but if you say ‘psychosis’—God forbid!!!... When I recovered from my

first episode, I tried to explain [to my previous employer] that I wasn't well and the like, and they were sort interested in that they asked whether my wife is still with me (laughs), but that was it. 'We can't do anything for you anymore', they said, and then they interrupted the conversation. It would have been better not to mention a word."

Difficulties are also encountered in *finding a partner or in maintaining an existing partnership*. For many, the unpredictable course of the illness, additional burden and fears of the partner led to a break-up. This often involves the separation from one's children. Thus the patients feel that the illness and the fears associated with it results in difficulties in filling family roles.

Subjective views of stigma: Different perspectives of schizophrenic patients, their relatives, and mental health professionals

As shown in Fig. 1, patients, relatives and mental health professionals each give emphasis to different types of stigma.

For all three groups, the largest share of all stigma and discrimination is experienced in *direct interaction with others*. Almost half of the stigmatisation experiences described by the patients concern this area (49%). Relatives (39%) and mental health professionals (38.7%) share the view that the reduction of social contacts in the interaction with others is the most central area in which stigma is encountered by those suffering from schizophrenia.

Public images of mental illness are the second most central stigmatisation experience of those suffering from schizophrenia. Of all three groups, mental health professionals attach the greatest importance to stigma experienced through negative public images of mental illness (34.4% of all mentions). In their eyes, stigmatisa-

tion through negative media reports is nearly as central as stigma encountered by the patients in the context of direct social interaction. Relatives (27.7%), too, place greater importance on the derogatory treatment of schizophrenia in the public discourse than the patients themselves (19.7%).

For schizophrenic patients, 13% of stigma and discrimination was experienced through imbalances and injustices inherent in *social structures, political decisions and legal regulations*. Mental health professionals consider this area as equally important (13.1%). Compared with the view of the patients, a striking focus of the relatives on stigma experienced through discriminatory structures and practices can be observed: they recount patients' experiences in this area twice as frequently as the patients themselves (27.1%).

Stigmatisation experiences reported by 18.3% of the patients' concern the exclusion from family, partnership, or professional roles. The *limited access to social roles* for schizophrenic patients is also an important aspect of the stigma of schizophrenia from the point of view of mental health professionals (13.8%). Relatives consider this area of stigma experiences as less central (6.2%).

Looking more closely at each of the dimensions, more subtle differences between the perception of the three groups become apparent. While the *patients'* experience of stigma is dominated by the hurt they experience through the loss of social contacts and the fact that the illness shapes people's perception of themselves, *relatives* feel that patients are particularly discriminated against through deficits in the quality of the treatment they receive, especially compared with health services available for patients with physical illness. In their eyes, the quality of mental health care is an indicator for the recognition of schizophrenia as an illness and the equal treatment of mental and physical illness. This may also account for their focus on structural discrimination. *Mental health professionals*, on the other hand, consider

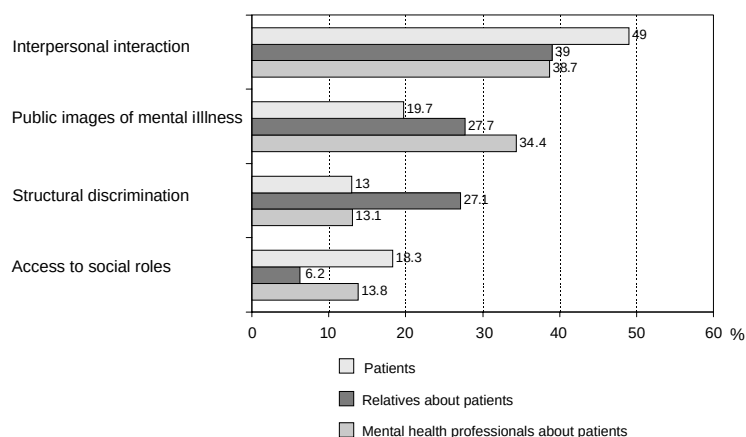


Fig. 1. Dimensions of stigma from the perspective of schizophrenic patients, their relatives and mental health professionals.

the fact that patients seek to conceal the illness from others as a consequence of negative public images of schizophrenia as the most central aspect of the stigma attached to the illness. The problems resulting from this in job search situations as well as the reluctance to seek psychiatric treatment caused by the shame attached to being mentally ill are at the centre of their attention in reflecting about the stigma experienced by people with schizophrenia.

Discussion

The domain of interpersonal interaction has been the emphasis of most previous stigma research. Researchers were centrally interested in how people with schizophrenia were perceived by others and in the way such perceptions affected micro-level interactions (cf. Oliver, 1992). This decidedly individualistic focus of research on stigma has obstructed the view for the more pervasive, socially shaped forms of stigma leading to an exclusion from social and economic life. Looking at the literature, there is a wealth of studies on stereotyping while the body of research on discrimination is far less extensive. In addition, those studies addressing discrimination focus the attention on the producers of rejection and exclusion rather than of the effects of discrimination on the “stigmatised” (Link & Phelan, 2001). The supposition that this research focus may produce an imprecise picture of stigma is supported by our results. The analysis of the focus group data shows that discrimination and disadvantages encountered as a consequence of schizophrenia reach far beyond the sphere of direct social interaction. In line with Goffman’s (1986) conceptualisation of stigma, those with schizophrenia first and foremost feel that their illness and the stereotypes associated with it often shape people’s perception of them and thus impose an illness identity on them, regardless of whether they currently experience acute symptoms of the illness or not. The reduction of social contacts ensuing from problems in the interaction with others that follow this “split between self demands and self” (Goffman, 1986, p. 5) is perceived as the central area in which the stigma of schizophrenia is experienced. However, according to our findings, only half of the patients’ stigmatisation experiences are made in direct personal contact with others. There are other areas in which stigmatisation does not only occur, but is also perceived by those at the receiving end of stigma as negatively affecting their life chances and quality of life. Beyond the domain of social interaction, stigma is experienced through structural imbalances built into legal regulations, health insurance statutes and political decisions as well as through the stereotypical, largely negative attitudes of the public and the media portrayals reflecting and reinforcing these stereotypes. Here, the

views of those who are exposed to stigma in their daily lives lend support to Link and Phelan’s (2001) conceptual discussion in which they highlight the dependence of stigma on social, economic and political power.

The patients’ account of their stigma experiences is confirmed by the relatives and mental health professionals. Being in regular and often close contact with those suffering from schizophrenia, they observed incidences of stigma and discrimination ensuing from it in the same areas as the patients themselves. The reports of stigmatisation experiences shared with them on the part of their ill family members, or patients, respectively, are in accordance with what the patients had to tell about the social consequences of suffering from schizophrenia.

While there is agreement between the three groups about the dimensions of stigma, they attach different weight to the four areas. Also, aspects of the experiences assume a different meaning, depending on who describes them and on the context chosen for recounting an experience. Considering the perspectives of patients, relatives and mental health professionals thus also allowed us to obtain a more comprehensive view of the stigma related with schizophrenia. Our results show that, with their different foci of attention, patients, relatives and mental health professionals each put emphasis on particular aspects of the problem and view stigmatisation in the light of their own everyday experiences and specific interests. For example, mental health professionals’ pronounced emphasis on public images of mental illness as an area of stigma experiences might be ascribed to the fact that they are less frequently witnessing stigmatisation of their patients in direct contact with others. Further, they are predominantly aware of stigma in areas that also concern themselves. For instance, the role and character of psychiatrists and stereotypical ideas of psychiatric treatment are also frequent subject of negative media portrayals (c.f. Walter, 1989).

This variation stresses the necessity to consider the perspectives of all groups involved in struggling with schizophrenia in order to get a comprehensive picture of how the stigma attached to the illness affects the patients’ quality of life, their self-esteem and their chances to benefit from optimal treatment services. The variations in the perceptions of the problem on the part of patients, relatives and mental health professionals further allow to consider aspects of stigma that might not be seen by either group alone.

This being an explorative study, it has a number of limitations in terms of the generalisability of results. It could be argued that, due to the small number of people questioned, the pattern of stigmatisation experiences found might not show the complete picture of the stigma associated with schizophrenia. Moreover, the patients participating in the focus groups were well functioning

at the time of the focus group meeting. Although many of them also had experienced severe episodes of schizophrenia and longer periods of in-patient treatment, the view of those currently in an acute illness phase or in long-term residential care might differ from the perspective of those questioned in our study. They may encounter stigma in other areas, are likely to be less exposed to community reactions or reflect less about how public stereotypes might influence the behaviour of others towards them while they struggle with acute symptoms of the illness. However, it was our objective to explore subjective views of stigma from the starting point of the concrete experiences of schizophrenic patients and those witnessing their situation in everyday life. Here, the qualitative approach chosen has the advantage of affording a view of stigma which is informed by actual incidences of stigmatisation described by the patients, relatives and mental health professionals. In addition, generating a typology of stigma experiences from verbal statements allows to illustrate the reasoning behind stigma categories and the mechanisms by which particular discriminating behaviours and structures affect the lives of the “recipients” of stigma. Here, our results can be valuable in interpreting findings of attitude research with regard to the extent to which there is a connection between public beliefs about mental illness and the stigma experienced by those suffering from it. The dimensions of stigma found in the focus groups may further serve as a basis in developing assessment instruments for subjectively “felt” stigma that can be employed at a more representative level.

Conclusions

Patients, relatives and mental health professionals agree in their view that the stigma because of schizophrenia reaches beyond the individual level. The agreement between the three groups widens the scope of support for the criticism that stigma research has turned a blind eye on the role of structural aspects and societal mechanisms in the production and maintenance of stigma and discrimination. Future research should be informed by a conceptual understanding that takes account of institutionalised forms of stigma. The knowledge that stigma goes beyond interpersonal interaction is of particular relevance in designing effective anti-stigma interventions. While it is important to provide support for schizophrenic patients in coping with stigma through a training of social competencies and cognitive therapies changing negative images of the self resulting from stigma (Corrigan, 1998), strategies to reduce stigma and discrimination have to address all four dimensions of stigma if they are to be successful.

A central area for intervention are the media. Media portrayals, especially those associating schizophrenia with criminal violence, are experienced as personally devaluating and hurtful. Beyond doubt, the media exert a crucial influence in the production of stereotypical images (cf. Philo et al., 1994; Wahl & Lefkowitz, 1989; Wahl, 1995). This implies, however, that they can also be a powerful vehicle for changing stigmatising representations of schizophrenia. Thus, co-operation with the media is essential if we are to effectively counteract negative media coverage and the lack of information on schizophrenia among the public.

In order to challenge structural disadvantages, political decision-makers and health care planners must be important target groups. Political lobbying alerting to an unequal treatment of mental and physical disorders, e.g. with regard to health insurance coverage, is called for as well as a stronger consideration of the needs of patients and relatives in the provision of mental health services. With the recent focus on quality assurance and treatment effectiveness in health care, quality of life is increasingly defined as an important outcome measure of psychiatric treatment. In this context, current services should be reviewed in the light of whether they are tailored to the needs of schizophrenic patients and their families. In addition, general health care providers must be better informed about mental disorders to assure that schizophrenic patients receive adequate treatment for physical complaints.

In order to challenge the exclusion of people with schizophrenia from important life chances, it is particularly important to support them in the field of employment. A close co-operation between the mental health services and employers in finding suitable arrangements for the re-entry of patients in the labour market and job coaching services arranging job placements in line with the skills and capabilities of the patients are a starting point in improving the situation. In addition, structural changes in the labour market, such as allowing for more flexible, part-time work arrangements are called for.

Finally, first hand information from patients and relatives is essential if attempts to combat stigma are to be successful, i.e. that they make a difference for the lives of those facing obstacles to their social integration on the basis of negative attributes associated with their illness. The involvement of patients and relatives in anti-stigma programmes may further give them a sense of empowerment, enhance their self-esteem and mobilise their stigma coping skills. This realisation has guided the approach of the World Psychiatric Association whose Global Programme against Stigma and Discrimination because of Schizophrenia is based on the premise that mental health experts join forces with the experts in dealing with stigma in their daily lives: those suffering from schizophrenia and their families (Sartorius, 1998). They should be partners both in research on stigma and

in programmes to counteract stigma and discrimination. The study presented here has shown how valuable the insights facilitated by exploring their views can be.

References

- Angermeyer, M. C., & Matschinger, H. (1995a). In Das Bundesministerium für Gesundheit (Ed.), *Auswirkungen der Reform der psychiatrischen Versorgung in den neuen Ländern der Bundesrepublik Deutschland auf die Einstellung der Bevölkerung zur Psychiatrie und zu psychisch Kranken. Ergebnisse einer empirischen Untersuchung*. Baden-Baden: Nomos Verlagsgesellschaft.
- Angermeyer, M. C., & Matschinger, H. (1995b). Violent attacks on public figures by persons suffering from psychiatric disorders: Their effect on social distance towards the mentally ill. *European Archives of Psychiatry and Clinical Neuroscience*, 245, 159–164.
- Angermeyer, M. C., Matschinger, H., & Riedel-Heller, S. G. (1999). Whom to ask for help in case of mental disorder? Preferences of the lay public. *Social Psychiatry and Psychiatric Epidemiology*, 34, 202–210.
- Angermeyer, M. C., & Schulze, B. (2001). Reinforcing stereotypes: How the focus on forensic cases in news reporting may influence public attitudes towards the mentally ill. *International Journal of Law and Psychiatry*, 24, 469–486.
- Becker, H. S. (1963). *Outsiders. Studies in the sociology of deviance*. New York: Collier-Macmillan.
- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data. Complementary research strategies*. Thousand Oaks, London, New Delhi: Sage Publications.
- Conrad, P. (1990). Qualitative research on chronic illness: A commentary on method and conceptual development. *Social Science and Medicine*, 30, 1257.
- Corrigan, P. W. (1998). The impact of stigma on severe mental illness. *Cognitive and Behavioural Practice*, 5, 201–222.
- Farina, A., & Felner, R. D. (1973). Employment interviewer reactions to former mental patients. *Journal of Abnormal Psychology*, 82, 268–272.
- Farina, A., & Ring, K. (1965). The influence of perceived mental illness on interpersonal relations. *Journal of Abnormal Psychology*, 70, 47–51.
- Farina, A., Thaw, J., Lovern, J. D., & Mangone, D. (1974). People's reactions to former mental patients moving to their neighbourhood. *Journal of Community Psychology*, 2, 108–112.
- Fink, P. J., & Tasman, A. (Eds.). (1992). *Stigma and mental illness*. Washington DC: American Psychiatric Press.
- Finzen, A. (1996). *Der Verwaltungsrat ist schizophoren. Die Krankheit und das Stigma*. Bonn: Psychiatrie-Verlag.
- Flick, U., v. Kardorff, E., Keupp, H., v. Rosenstiel, L., & Wolff, S. (Eds.). (1995). *Handbuch qualitative Sozialforschung. Grundlagen, Konzepte, Methoden und Anwendungen*. Weinheim: Psychologie Verlags Union.
- Goffman, I. (1986). *Stigma. Notes on the management of spoiled identity*. New York: Touchstone.
- Huberman, A. M., & Miles, M. B. (1994). Data management and analysis methods. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 428–444). Thousand Oaks, London, New Delhi: Sage Publications.
- Huxley, P. (1993). Location and stigma: A survey of community attitudes to mental illness—Part I. Enlightenment and stigma. *Journal of Mental Health*, 2, 73–80.
- Knodel, J. (1993). The design and analysis of focus group studies: A practical approach. In D. Morgan (Ed.), *Successful focus groups. Advancing the state of the art* (pp. 35–51). Newbury Park, London, New Delhi: Sage Publications.
- Krüger, R. A. (1994). *Focus groups: a practical guide to applied research*. Thousand Oaks, CA: Sage Publications.
- Kuckartz, U. (1988). *Computer und verbale Daten*. Frankfurt am Main: Peter Lang.
- Kuckartz, U. (1998). *WinMAX. Professionelle Version. Handbuch zum Textanalysesystem WinMAX für Windows*. Opladen: Westdeutscher Verlag.
- Lawton, R., & Parker, D. (1999). Procedures and the professional: The case of the British NHS. *Social Science and Medicine*, 48, 352–361.
- Lemert, E. M. (1951). *Social pathology*. New York: MacGraw Hill.
- Link, B. G. (1982). Mental patient status, work, and income: An examination of the effects of a psychiatric label. *American Sociological Review*, 47, 202–215.
- Link, B. G. (1987). Understanding labeling effects in the area of mental disorders: An assessment of the effects of expectations of rejection. *American Sociological Review*, 52, 96–112.
- Link, B. G., Cullen, F. T., Frank, J., & Wozniak, J. F. (1987). The social rejection of former mental patients. Understanding why labels matter. *American Journal of Sociology*, 92, 1461–1500.
- Link, B. G., Cullen, F. T., Struening, E., & Shrout, P. E. (1989). A modified labelling theory approach to mental disorders: An empirical assessment. *American Sociological Review*, 54, 400–423.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385.
- Link, B. G., Struening, E. L., Rahav, M., Phelan, J. C., & Nuttbrock, L. (1997). On stigma and its consequences: Evidence from a longitudinal study of men with dual diagnosis of mental illness and substance abuse. *Journal of Health and Social Behavior*, 38, 177–190.
- Madriz, E. (2000). Focus groups as feminist research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 835–850). Thousand Oaks, London, New Delhi: Sage Publications.
- Morgan, D. (1997). *Focus groups as qualitative research (Qualitative research methods, Vol. 16)*. Thousand Oaks C.A.: Sage Publications.
- Nunnally, J. C. (1961). *Popular conceptions of mental health*. New York, NY: Holt, Rinehart and Winston.
- Oliver, M. (1992). *The politics of disablement*. Basingstoke: MacMillan.
- Page, S. (1977). Effects of the mental illness label in attempts to obtain accommodation. *Canadian Journal of Behavioural Science*, 9, 193–199.
- Phelan, J. C., & Link, B. G. (1998). The growing belief that people with mental illnesses are violent: The role of the dangerousness criterion for civil commitment. *Social Psychiatry and Psychiatric Epidemiology*, 33(Suppl. 1), 7–12.

- Phelan, J. C., Link, B. G., Stueve, A., & Pescolido, B. (1997). *Public conceptions of mental illness in 1950 and 1996: Has stigma declined?* Paper presented at the Annual Meeting of the American Sociological Association, Toronto.
- Philo, G., Secker, J., Platt, St., Henderson, L., McLaughlin, G., & Burnside, J. (1994). The impact of the mass media on public images of mental illness: Media content and audience belief. *Health Education Journal*, 53, 271–281.
- Piner, K. E., & Kahle, L. R. (1984). Adapting to the stigmatising label of mental illness: Forgone but not forgotten. *Journal of Personality and Social Psychology*, 47, 805–811.
- Roche, A. M., Guray, C., & Saunders, G. B. (1991). General practitioners' experiences of patients with drug and alcohol problems. *British Journal of Addiction*, 86, 263–278.
- Rosenfield, S. (1997). Labeling mental illness: The effects of received services and perceived stigma on life satisfaction. *American Sociological Review*, 62, 660–672.
- Sartorius, N. (1998). Stigma: What psychiatrists can do about it? *Lancet*, 325 (9133), 1058–1059.
- Silverman, D. (2000). *Doing qualitative research. A practical handbook*. London, Thousand Oaks, New Delhi: Sage Publications.
- Sirey, J. A., Bruce, M. L., Raue, P., Perlick, D. A., Alexopoulos, G. S., & Meyers, B. S. (1999). *Psychological barriers in young and older outpatients with depression: Predictors of treatment discontinuation*. Paper presented at the American Association of Geriatric Psychiatry, 12th Annual Meeting, New Orleans, LA. March 14–17, 1999.
- Steward, D., & Shamdasani, P. (1994). *Focus groups: Theory and practice*, Vol. 20. Applied Social Research Method Series. Newbury Park: Sage Publications.
- Taylor, S. M., & Dear, M. J. (1981). Scaling community attitudes toward the mentally ill. *Schizophrenia Bulletin*, 2(7), 225–240.
- Wahl, O. F. (1995). *Media madness: Public images of mental illness*. New Brunswick, NJ: Rutgers University Press.
- Wahl, O. F., & Lefkowitz, J. Y. (1989). Impact of a television film on attitudes toward mental illness. *American Journal of Community Psychology*, 7(4), 521–528.
- Wakefield, M., Reid, Y., Roberts, L., Mullins, R., & Gillies, P. (1998). Smoking and smoking cessation among men whose partners are pregnant: A qualitative study. *Social Science and Medicine*, 47, 657–664.
- Walter, G. (1989). The stereotype of the mad psychiatrist. *Australian and New Zealand Journal of Psychiatry*, 23(4), 547–554.
- Wolff, G. (1997). Attitudes of the media and the public. In J. Leff (Ed.), *Care in the community: Illusion or reality?* (pp. 145–163). London: Wiley.