

ORIGINAL PAPER

Miguel Angel González-Torres · Rodrigo Oraa · Maialen Arístegui · Aranzazu Fernández-Rivas · Jose Guimon

Stigma and discrimination towards people with schizophrenia and their family members

A qualitative study with focus groups

Accepted: 6 September 2006 / Published online: 11 October 2006

Abstract *Background:* There is a scarcity of data regarding the actual stigma and discrimination experienced by schizophrenic patients and their relatives. Those experiences can vary significantly depending on the specific social group involved. We have explored such phenomena in our culture with a qualitative technique. *Methods:* We developed a qualitative study with focus groups of clinically stable schizophrenic outpatients ($N = 18$) and relatives ($N = 26$). Three groups were performed in each sample. *Results:* Six categories of stigma and discrimination experiences were extracted from the patients' data: Mental illness vs. Lack of will, Prejudice related to dangerousness, Over-protection-infantilization, Daily social discrimination, Discrimination in health care, Descendants, Avoidance-social isolation. Data from relatives were divided into three sets: discrimination towards the patients witnessed by relatives, discrimination suffered by the relatives themselves and discrimination exerted by the relatives on the patients. *Conclusions:* Patients and relatives describe a great variety of stigma and discrimination experiences in all areas of life, including health care. Isolation and avoidance are common reactions to those experiences. Publicizing these stigma and discrimination experiences could help to reduce stigmatizing attitudes in society and result in healthier

reactions from patients, favoring a better course of the illness.

Key words schizophrenia – stigma – discrimination – qualitative research – focus groups

Introduction

Throughout history, mental illness has been interpreted in many different ways, depending on the beliefs of each culture. In social settings like our own, mental illness has almost always had negative connotations. The mentally ill have been discriminated against in several ways throughout the centuries.

Expressions such as “mentally ill” or “mental patients” are still associated with violence, dangerousness, unpredictability, and even moral depravity. [1] Compared to other mental illnesses, schizophrenia tends to be linked to negative media coverage and public imagery. [2] Public fear and negative stereotypes remain an obstacle to the adequate use of effective treatment and social integration of the patient. [3] Negative attributions can be detected in western [4] and non-western societies [5].

To explain how this stigmatization and discrimination process develops, Link and Phelan [6] have described four stages: labeling, negative stereotyping, separation (“us” from “them”) and, finally, loss of status and discrimination. Political, economic, and social powers shape the prejudice and discrimination experienced by the mentally ill. These factors can explain the different ways in which the mentally ill are subject to disapproval and discrimination.

Persons with schizophrenia are probably the mentally ill patients who mostly suffer from stigma. The effects of discrimination work almost like a second illness that acts in several ways, not only in interpersonal relationships but also in social roles and

M.A. González-Torres · J. Guimon
Dept. of Neuroscience
Basque Country University
Bilbao, Spain

M.A. González-Torres (✉) · R. Oraa · M. Arístegui
A. Fernández-Rivas
Psychiatry Service, Basurto Hospital
Avda. Montevideo 18
48013 Bilbao, Spain
Tel.: +34-94/400-6066
Fax: +34-94/400-6213
E-Mail: mtorres@hbas.osakidetza.net

at the social construct level. These experiences constitute an important barrier to the patient's clinical improvement and mental health, restricting opportunities and lowering self-esteem.

The pioneers in the field of stigma were Goffman [7] and Scheff [8], and Allport [9] in the extensive field of the sociology of prejudice. Today, stereotypes of this nature once again occupy a relevant position in current publications [10]. An example would be certain European works such as *The Image of Madness* [11], the file on "Stigma of Mental Illness" comprising about ten contributions ([12] and [13], for instance) and the series of articles published in the *Schizophrenia Bulletin* by Penn et al. [14], Boisvert et al. [15], Wahl [16], and others.

One common denominator of these and many other works on the subject is the fact that the study of (mainly negative) attitudes and representations is conducted on individuals who do not face stigmatization personally. The great majority of the studies are conducted on the larger community, among health professionals and students. Very few studies include people directly concerned with stigmatization, that is, patients and ex-patients who suffer mental illness, particularly schizophrenia, in their social setting.

In 1996, the World Psychiatric Association launched a program against the stigma of schizophrenia [3, 17, 18], recognizing the importance of this problem and starting an effort to reduce stigma and discrimination in groups related to this illness and the general population. This initiative against stigma is now present in almost 20 countries. A wide campaign to fight the stigma of schizophrenia was also carried out in Spain [19], first in Madrid and later in other regions. In 2001, the World Health Organization (WHO) identified stigmatization as one of the obstacles to mental health program development [20], alerting public institutions worldwide about the importance of the problem and giving political coverage to initiatives launched in different countries.

Stigma experienced by people with schizophrenia and those close to them are strongly influenced by the historical, social, education, and cultural characteristics of the group to which they belong. This means that it is always difficult to generalize findings from one country or specific group to others. Past research has shown a clear need for local understanding [21–24]. Findings can sometimes be counterintuitive, as in a German study in which patients in a traditional psychiatric hospital perceived less devaluation and discrimination than others admitted to a general hospital psychiatric ward [21], or an American study [22] showing that families tended to conceal their relatives' mental illness less when positive symptoms were more severe.

Sometimes, different ethnic communities living together in the same country present different levels of stigma [23], and traditional societies in developing

countries show marked negative attitudes and stereotypes towards, people with schizophrenia and other psychiatric illnesses, in spite of the extended belief in more tolerant attitudes in such societies [5]. There is also a trend in current research in this field [24], whereby the focus on stigma is giving way to a focus on discrimination. This provides for a more pragmatic approach, closer to people's worries and their daily lives, and also closer to other historical fights such as human rights or racial discrimination. Focussing on discrimination requires a very precise local understanding of institutions, laws, history, etc., in every place where anti-discrimination campaigns are to be implemented.

In this vein, most programs already carried out have made an effort to reach an understanding of local conditions and attitudes. It is therefore inadvisable to simply extrapolate data obtained from several different societies. A clear picture of stigma and discrimination in schizophrenia requires studies in diversified social settings.

We therefore decided to study a concrete aspect of the broad problem of schizophrenia-related prejudice in our setting. We were particularly interested in approaching the actual stigma and discrimination experienced by persons with schizophrenia and their families. Our goal was to explore situations experienced by patients and their families in which they had felt mistreated because of their (or their relative's) schizophrenia. Obviously, this strategy cannot uncover real existing discrimination unnoticed by patients or families, which is outside the purpose of our study.

The project was developed in Biscay, a province in the Basque Country in northern Spain. There is a well-developed public health system, offering universal care. Most of the region's population lives around Bilbao, forming a conurbation of 1 million people. The population's mental health needs are attended to mainly through a network of public Community Mental Health Centers (CMHCs) and inpatient units in General or Psychiatric Hospitals. Resources such as Day Hospitals or Rehabilitation Units are linked to CMHCs or Hospital Units.

We considered that it was important to focus on actual stigma and discrimination experience rather than on opinions about existing stigma. We focussed on episodes recalled and witnessed by patients and their family members. Our intention was to make a distinction between actual experience and the patients' and families' views of current social tendencies in relation to their circumstances. A study of family members was important for two reasons. First, they are first-hand witnesses of any discriminatory attitudes experienced by their mentally ill family members. Second, they may have experienced stigma and discrimination themselves, simply because they are relatives of, and live with, a mentally ill person.

Qualitative methodology has been applied to the study of stigma in schizophrenia, but in a very limited way. In a comprehensive review of papers focussing on measuring stigma in mental health, Link et al. [25] found only 17 qualitative studies in a sample of 123. However, the authors recognize the advantages of qualitative techniques for studying the subjective experience of stigma and providing a deeper understanding of the whole process.

Aims of the study: to (i) explore actual stigma and discrimination experience recalled by people with schizophrenia and (ii) relatives of people with schizophrenia; and (iii) reflect on the consequences of those experiences on patients, relatives, and society in general.

Methods

For our study, we selected a specific qualitative method: focus groups. This technique was developed by social scientists in the 1930s. Focus groups, forgotten by academics who preferred to concentrate on quantitative processes, were extensively used for pragmatic market studies. In the 1980s, their academic uses were rediscovered and, since then, focus groups are used in many sciences, including several medical fields [3].

Focus groups consist of 6–12 people who share certain common characteristics. Sessions are held on a specific topic and last between 1 and 2 h. Participants express their opinions and listen to the responses of others, which in turn provoke further comment. The quality of these added observations is generally higher than the initial ones. They provide new and varied information and points of view that can be subsequently discussed.

■ Sample selection. Group composition

We performed non-random sampling, intentionally selecting cases we considered rich in information and comprising several diverse population segments for the study. We followed a theoretical sampling [26, 27] principle. All patients should be clinically stable. The interesting patient characteristics sought and the three groups formed were:

- Long-term patients (LTP) with schizophrenia (diagnosed over 5 years ago), selected from among patients who had attended group therapy sessions at our hospital for years.
- Short-term patients (STP) (diagnosed with schizophrenia less than 5 years ago) selected from among patients attending our outpatient clinics at our hospital. Generally, these patients had been admitted in recent years and were attended at these units.
- Patients with schizophrenia (AP) belonging to a local association of mental health patients and their relatives, and who took part in the association's activities. We approached a local association for subjects with psychiatric illnesses and their families.

We also formed three groups of relatives. We selected preferably close family members who lived with a schizophrenic patient, generally the mother, father, or siblings. The characteristics sought were:

- A group of relatives related to some of the LTP who came to our hospital's Day Hospital Service (LTF).
- A group of relatives of STP who had been in the Acute Unit in the past 3 years (STF).
- A group of relatives who took part in the activities of a local association for people with psychiatric illnesses and their families (AF).

Table 1 Focus group composition. Number of participants

	Male	Female	Total
<i>Patients</i>	9	9	18
Long-term duration. Group therapy (LTP)	3	2	5
Short-medium-term duration. Outpatient clinics (STP)	3	2	5
Association patients (AP)	3	5	8
<i>Family members</i>	6	20	26
Long-term duration. Day hospital (LTF)	4	8	12
Short-medium-term duration. Old admittance (STF)	2	5	7
Association families (AF)	0	7	7
<i>Total</i>	15	29	44

A total of 44 people were interviewed. Of these, 18 were patients and 26 were family members. Two-thirds were women. Table 1 shows the group compositions. The patients and their families were contacted through the heads of the health centers and the Association. Potential participants were informed of the study and, if agreed, gave their consent.

■ Focus groups and data collection

Sessions were recorded on audio and video. Special care was taken to avoid reproducing the therapeutic atmosphere to which patients were accustomed. Group participants were received by the researchers themselves, in order to avoid delays and help them feel at ease. On each occasion, two researchers led the groups, and both the pair of researchers and the role they played changed for each group session. The group leader for each session was MAGT, MA, or RO. One of these researchers assumed the role of leader and the other one acted as joint leader and observer. The latter took field notes which were subsequently used for the initial analysis at the end of each group session.

Sessions were systematically based on a limited, pre-defined number of topics. The topics were chosen from areas in which participants might have experienced stigma or discrimination. Topic selection was based on a previous brainstorming session among the researchers, several individual interviews, and an earlier test group. The chosen topics are given in Fig. 1.

The question-and-answer model was avoided and replaced by raising various topic areas in a flexible way and in no pre-established sequence, in order to take advantage of any changes of topic suggested by the groups. Each area was gradually explored in greater depth. Differing points of view and discussion were encouraged, with special emphasis on the neutrality of the moderators. The classic structure of opening questions, introductions, key questions, and end questions was followed. Focus group interviewing techniques and the analysis of collected data are described in the work of Krueger and Casey [28], Morgan [29], Casey [30], and Morgan and Krueger [31].

■ Data analysis

Field notes were taken during the group sessions and subsequently summarized. These notes supported the subsequent analysis and helped to make adjustments for subsequent group sessions.

Once the recordings and transcripts had been made, the analysis consisted of several stages, which are shown in the outline below. First, each individual researcher became familiar with the material (complete transcripts of recordings plus field notes). Comments were then assigned a category and classified by pooling them with other comments in the same category, and any comments devoid of useful information were discarded. Differing levels of attention were given to comments according to their frequency, whether they coincided with comments made by other groups and interviewees, the emotions they awakened in the participants and

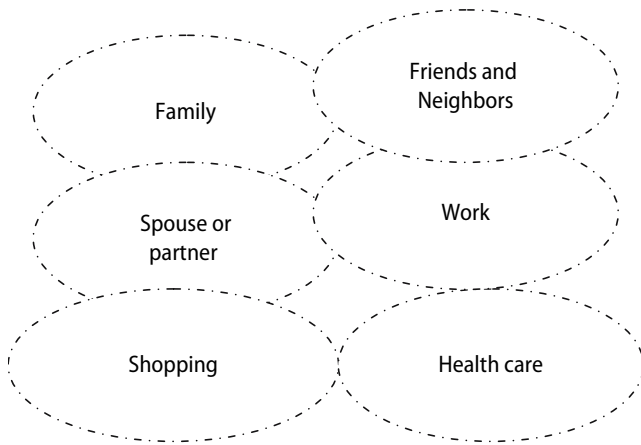


Fig. 1 Areas explored

their specificity in relation to the purpose of the study. Summaries of the different categories were made. Code mapping was performed following Krueger and Casey's [28] "long table" approach, with the help of word processing software replacing the traditional pen-and-paper procedure. Initially, blocks of text containing comments from participants were studied from the point of view of the topics selected for exploration. As new comments appeared, these initial categories were segmented, or new categories adding new information on the subject were created. Comments from later groups helped to restructure the categories until the end of the data gathering process.

During the second stage, the categories found were shared among the researchers. They were revised, differences of criteria were discussed, and a consensus was reached where necessary. The data were then interpreted in the context of the original transcripts and the literature. Fig. 2

Results

Most patients and relatives provided comments on their personal experience of stigma and discrimination. One person out of the total of 44 participants in

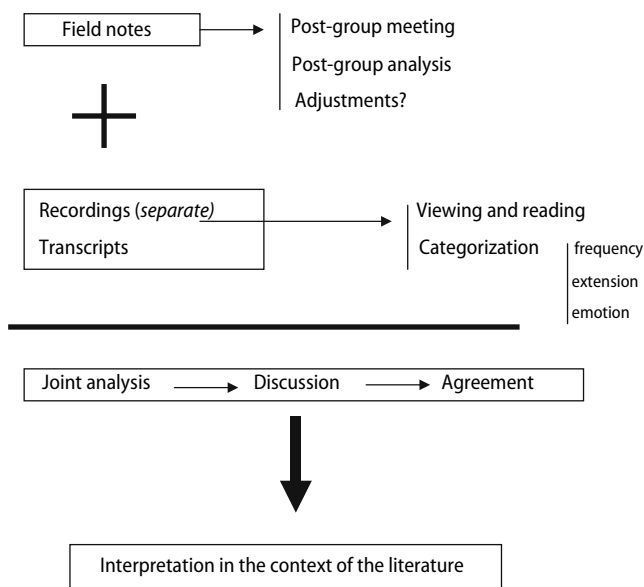


Fig. 2 Outline of data analysis process

the family groups, and three people out of 26 in the groups of schizophrenics, failed to describe any experiences.

Following the complex systematic analysis described above, we grouped the stigma and discrimination experiences into the categories below. First, we separated the categories perceived by the patients from the categories perceived by the family members. The latter referred to a variety of experiences that depended on the role of the family member. Sometimes, they spoke as first-hand witnesses of stigma and discrimination towards their mentally ill family members. In other cases, they referred to their own experience as the recipients of discriminatory behavior based on a member of their family being mentally ill. Finally, they themselves might discriminate against their mentally ill family members (Table 2).

Patients

During the focus group sessions, as we had intended with the selection, the schizophrenic patients gave no sign of significant symptoms and showed good verbal ability. On occasion, the patients tended to spontaneously explain their personal experience with their illness, making it necessary to redirect the group focus towards the pre-selected areas. We focussed on the aim of the study, and they co-operated and easily expressed their overall feelings of stigma and discrimination, going on to describe concrete experiences. The various areas are summarized below with some of the more significant sentences.

1. Mental illness vs. Lack of Willpower

One of the largest categories was the stigma perceived by patients regarding the attribution of lack of willpower to some of their conduct. They reported having experienced a lack of understanding that their acts were illness-related, and even having been accused of being "lazy" or "overdramatic."

"The psychologist... told me that my illness was there because I had invented it... the family doctor... didn't believe what I had, that I was ill... he said that I was asking for sick leave because I didn't want to work.." (B; female, 27 years old).

They believed that ignorance about their illness led even those closest to them to fail to understand that their behavior was part of their symptoms.

2. Prejudice Related to Dangerousness

They also made extensive and particularly intense references to instances in which they had been treated as being dangerous, unpredictable or "psychopaths," due to their condition. They considered that the prejudice of dangerousness surrounding mental illness caused the people in their environment to show

Table 2 Fields of stigma and discrimination experienced

Patients	Family members
	<i>As witnesses:</i>
(1) Mental illness vs. lack of will	(1) Prejudice
(2) Prejudice related to dangerousness	(2) Job-related discrimination
(3) Over-protection-infantilization	(3) Discrimination by friends
(4) Daily social discrimination	(4) Isolation-protection
(5) Discrimination in health care	(5) Abandon-nihilism
(6) Descendants	<i>As subjects:</i>
(7) Avoidance-social isolation	(1) Guilt-isolation
	(2) Disrespect in health care
	(3) Shame and concealment
	<i>As actors:</i>
	(1) Over-protection-infantilization

fear when they met them in the hallway and in similar situations.

"I took the elevator and my neighbor was leaving and she was frightened. She always gets frightened" (C; male, 45).

Other times, they were treated as if they were going to cause problems.

"... We don't want people like you around and so on" (C; male, 45).

They also commented on the staff's expectations at the health centers they attended, which they considered to be discriminatory.

"(at the Psychiatric Hospital) we were told that the coffee machine wouldn't last long because certain aggressive people would break it" (D; female, 37).

They accused the media of playing an important role in maintaining these prejudices, since they offer an unreal image of schizophrenics, attributing the more serious crimes to them.

"The media... as soon as something happens... someone gets killed... it was a mentally disturbed person who had schizophrenia" (E; male, 50).

3. Over-protection-Infantilization

The relationship established between carers and persons with schizophrenia is generally very intense and there is often a fear of eventual relapse. In patients' perception, this situation causes over-protection, precisely by those who are closest to them, who interpret changes in their behavior with fear (they could be a sign of relapse), or hide sensitive information. Patients felt that this restricted their individuality and their opportunities for personal growth, beyond the limitations of the illness itself.

"Only because I'm getting up early in the morning... they start to say you're becoming a little like this, you're beginning to do that. Because of my illness, my family thought I couldn't do anything on my own and so they did everything for me." (G; female, 48).

"My mother lied to me about a lot of things that have hurt my feelings because I had to find out from others; about the death of a relative and things like that." (D, female, 37)

4. Daily Social Discrimination

Under this heading, we grouped everyday experiences that made patients perceive that they were treated differently when people were aware of their condition. They mentioned that they were relegated to the end when standing in line in shops, that they were not respected at work, or that they were treated as "oddballs" or with pity. The same was true when they searched for a place to live or when it was time to pay the check.

"The waiters over there at the S., it may take them 15 min to serve me; they always leave me 'till last.'" (C; male, 45).

"I sell my watercolours and they use me: they barter with me, they lower the price, they lower me by taunting me and saying 'that guy is crazy'—I have failed many times at my job but the bottom line is that my bosses, when they learn (that) I am mentally ill..." (C; male, 45).

5. Discrimination in Health Care

This is a particularly sensitive area for several reasons. First, due to the chronic nature of the illness and treatment requirements, schizophrenia patients need a close and trusting relationship with their doctors, nurses, and social workers. Second, one would expect this group to be better informed on mental illness and therefore less discriminating. Apart from isolated instances of abuse, the patients mentioned the various ways in which they noticed that they were treated differently from other patients due to their mental illness. They felt that, simply because of their schizophrenia, they were not believed, or the seriousness of their symptoms was underestimated, when they showed somatic symptom. In addition, they felt that they were not seen as an important party for receiving information or being included in the decision-making process regarding treatment.

"Until they discovered what I have (kidney stones), they didn't listen to me, it was all due to nerves, whenever I said my stomach ached, this side ached, it was nerves..." (H; female, 38).

"They ran all kinds of tests. They left me in hospital... they put me in a cubicle, they gave me serum and they didn't tell me anything. The next day they allowed me to leave the hospital. They didn't explain what I had or what I no longer had." (D; female, 37)

6. Descendants

Schizophrenia carries a high genetic component: the risk of schizophrenia is around 11 times greater in relatives of schizophrenic probands than in relatives

of matched control probands [31]. This is therefore a particularly complex issue in the lives of people with schizophrenia. They described various different situations in which they were mistreated when they mentioned the possibility of having children. Without genetic consultation of any kind, health professionals and family members alike often stated their complete opposition. This situation reaches such degrees that permanent contraceptive measures are sometimes taken without adequate consideration for the patient's opinion.

"You mention to the psychiatrist that you want to have a child and he says 'no, that's not possible, don't even think of it'" (D; female, 37).

"My mother had my (fallopian) tubes tied. I was under legal age; they did it to me when I was 17" (I; female, 32).

7. Avoidance—Social Isolation

This category groups a variety of comments, sometimes—though not always—with self-criticism, referring to situations in which the patients play an active part in discrimination. Due to the way others perceive them, their own prejudices or the way they think others perceive them, and also due to the limitations of the illness itself, they end up isolating themselves from their friends, they stop working and end up close to social isolation.

"It bothers me a lot because we are all like sheep and a lot of them stand out, you can tell their mental traits.... I don't have any friends because I left them all" (H; female, 38).

"I was annoyed by my fellow workers and suddenly one morning I hung my work clothes on the hanger and went home" (D; female, 37).

■ Family members

When evaluating the results of the family member focus groups, it is evident at first glance that more than three-thirds of the participants are women and, more specifically, mothers. Mothers are more involved in the daily care of the patients, and they take a more active role in the associations. This is a constant fact in our culture in all areas of medicine: it is the female members who are mostly responsible for the patients' care.

Family members' data can be grouped into three categories, depending on the role played in a discrimination situation. First, we refer to their role as first-hand witnesses of the stigma and discrimination experienced by people with schizophrenia. We then mention the fields in which family members refer to discrimination directed against them. Finally, we will find that a third role can be inferred from their comments, in which they themselves discriminate against the mentally ill.

As witnesses

1. Prejudice

This category groups various situations in which family members have witnessed instances of discrimination based on existing prejudice towards mental illness in the people in their social setting, including very close family, and the media. They have often heard the mentally ill accused of undesirable traits, such as being lazy, dangerous, and liars.

"My eldest son...says that he (the patient) will get well when he feels like it" (J; mother of a patient, focus group 3)

"... Whenever there's a psychosis about a violent death, they always mention mental disorders, it seems as though they always give the news from that angle. Generally, the news hits the headlines that way" (K; father, focus group 1).

2. Labor Discrimination

They perceived many instances in which their family members have suddenly lost their jobs, or their contracts have not been renewed. They attributed such situations to mental illness.

"...He was working very well... he had a crisis... the contract is still in force... I talked with the staff manager and he told me not to worry...it was because they were laying off workers" (L; mother, focus group 3).

3. Discrimination by Friends

Family members talked of various situations, in which they felt that the patient's friends did not respect their limitations, or stopped calling and avoided their company.

"My son with his group of friends... they go out together and he says, Order me a bottle of water, I can't drink alcohol. When he comes back from the men's room, they've ordered him a beer" (M; mother, focus group 3).

"They enter a place and when he goes to the men's room, when he gets back he's all alone" (K; father, focus group 1).

4. Isolation-Protection

This category relates to the social contact avoidance reactions observed in the mentally ill. They believed that this was due to their limitations and to the discrimination to which they were exposed:

"My son (the patient) said: 'since I became afraid of not being up to the job... well, I stopped looking for work'. I think they are protecting themselves... because for him, going out means drinking... it's like self-protection, a way of defending themselves" (O; father, focus group 1).

5. Abandonment-Nihilism

In this area, family members mentioned several perceptions of an attitude of therapeutic nihilism,

principally by social workers and health carers. They felt that they did not do everything they should because the illness was deemed incurable.

“I’ve seen that the people who have worked with them for many years... they ignore him...I’ve already been told that if treatment isn’t going well after 6 months you have to change”(O; father, focus group 1).

As subjects

1. Guilt-Isolation

Families mentioned various experiences in which even the closest family members or health professionals made blaming remarks. Other times, they felt how people avoid them:

“The first doctor who saw my son really was judgmental... she even went so far as to say that he was jail-bait... and that my son’s illness is my own fault” (M; mother, focus group 3).

“They see you at the supermarket and they avoid you, they don’t speak to you any more. My own family says that it is because I spoiled him...” (P; mother, focus group 3)

2. Ignored in Health Care

In this area, family members perceived that in many instances they were not taken into account in the decision-making process or they were not listened to enough. They felt that their abilities and the difficulties of daily life with the mentally ill were not appreciated.

“They said to me, “Lady... the only one here who has a problem is you” and I said “how can I help it when you have me against the wall and have practically... done me in.” Well, they just sent her home. There is a tendency to just ignore us, they go directly to the patient, and they don’t inform you unless you really make sure they do (the psychiatrists)” (R; mother, focus group 3).

3. Shame and Concealment

Family members commented that, at times, discrimination was directed at themselves. They highlighted instances when they felt ashamed of being related to a schizophrenic person and that this led them to self-discrimination frequently involving concealment.

“Many times we are the ones who hide because of the pain” (T; mother, focus group 1).

“For instance, the first few years I was ashamed of having a son who was mentally ill” (M; mother, focus group 1).

“...He had to go to hospital... and we didn’t know the day before whether he could leave to go to the wedding and then it was as though everyone would know that he was ill... we had a hard time” (U; mother, focus group 6).

As actors

1. Discrimination towards the mentally ill was clearly perceived throughout the family member focus group sessions. The discriminatory comments principally concerned exaggerated worrying and over-protection that might evoke infantile behavior in the patient.

“At home we have to be really clever... we have to be careful not to make a mistake... I’m always making signs to my husband: “Careful, you might hurt his feelings” (U; mother, focus group 6).

“I think (they should work) for instance, in a protected workshop, where they will be forced to take their medicine” (R; mother, focus group 3).

Discussion

Few studies explore the stigma of schizophrenia using qualitative techniques, and only a few use focus groups. Among the latter, two recent studies are particularly worth mentioning: Pinfold et al. [33] used focus groups in a sample of psychiatric outpatients (various diagnoses) to explore patients’ priorities regarding anti-stigma and anti-discrimination campaigns. They also collected personal experiences of stigma and patients’ reactions to those experiences. Schulze and Angermeyer [3] used focus groups in a sample of schizophrenic patients, their relatives, and health professionals. The authors found four dimensions of stigma in their data: interpersonal interactions, structural discrimination, public image of mental illness, and access to social roles.

Most of the stigma and discrimination experienced was related to prejudice surrounding mental illness, such as symptoms of willfulness, laziness, and dangerousness. Their experiences focussed mainly on the family setting, where they felt over-protected, and on the health care setting, where they felt that they were not being taken into consideration. There were fewer comments on daily social life, including work, shopping, and friends. The patients tended to isolate themselves, probably in an attempt to protect themselves. This protective strategy is suggested as a hypothesis that would explain the findings of Angermeyer et al. [21]. It would explain why many of the experiences refer to family and health care circles, whereas other circles are mentioned less.

Patients’ isolation and their concealment of the illness are common findings in the literature [33–36]. Patients seem to assume the negative stereotype prevalent in society as a whole at some level, resulting in self-discrimination and isolation from the social environment [6, 37]. The social distance created by others towards people with schizophrenia compounds that isolation. Social distance is linked to patients’

level of social skills and the perceived strangeness that may follow [38].

Our data on stigma and discrimination experiences in health care coincide with findings in other studies [3]. They should be understood in the context of the loss of credibility perceived in their environment by people with schizophrenia [33]. It is disturbing to note that those experiences refer to general as well as mental health care. Non-psychiatrist physicians would tend to play down the importance of somatic complaints once they were aware that the patient carried the diagnosis of schizophrenia. Psychiatrists and other mental health clinicians would give less consideration to patients' ability to decide for themselves, adopting a nihilistic therapeutic attitude. All this could cause patients to assume that the negative stereotypes attached to schizophrenia applied to them. The ensuing reactions of isolation and concealment and the loss of self-esteem may contribute to reduce these patients' opportunities in all areas of life [39].

The assumption that persons with schizophrenia lack willpower usually comes from the patient's own family. This could be related to a loss of credibility and also to a defensive reaction from some relatives (mainly fathers or brothers) who seem better able to tolerate this belief in a feeble will than schizophrenia itself. This attitude, when present, contributes to a denial of the illness and the resulting lack of treatment compliance. Insufficient attention to the patient's real needs may be the next step in this process.

Prejudice related to dangerousness is also a frequent finding in the literature. Participants in our groups tended to associate that type of prejudice with the violent image of schizophrenia shown in the media. However, in their extensive review of the subject in US publications, Stout et al. [40] pointed to a dearth of data about the relation between exposure to media images and the stigma of mental illness.

Over-protection and infantilization arise as a category in both family and patient samples, giving more consistency to the findings. Cohen and Struening [41] reported two different basic attitudes towards mental illness: benevolence and authoritarianism. A benevolent disposition, visible in many comments from families in our study, could be at the foundation of behaviors perceived by patients as infantilizing. Infantilization makes the acquisition of mature social roles more difficult and favors self-discrimination.

Comments on the difficulties of becoming parents encountered by people with schizophrenia are seldom found in stigma studies. The patients in our sample perceived a markedly negative and disrespectful attitude in this area from families and health professionals alike. This attitude, fluctuating between the benevolent and the authoritarian poles, is often not based on a rational exam of available evidence about the heritability of the illness or a thorough assessment of a patient's ability to take care of a child.

Family members reported discrimination against them. They felt that any discrimination towards their mentally ill relatives was also directed against them. Angermeyer et al. [42] mention similar impressions. In general, they are aware of the prejudice against mental illness, particularly concerning violence and dangerousness. They attribute this mainly to ignorance and the media. They seem to be more aware of the patients' difficulties finding work and how this complicates their friendships and social life, than the patients themselves. Sometimes, they encourage the patients to avoid contact with healthy people because of the risk involved in trying to follow their lifestyle.

In relation to their own personal experience, family members admitted to feelings of guilt and blame, sometimes stemming from themselves and sometimes from others' comments and behavior. They often concealed the illness as much as possible. Although they mentioned situations in which they felt that they were being avoided, they admitted that they tended to conceal themselves, particularly during the first few years of the illness. In a study with families of psychiatric inpatients, Phelan et al. [22] reported that hospital admission was concealed in 50% of families and both the characteristics of the mental illness and the social characteristics of the family were significantly related to levels of family stigma.

Kadri et al. [5], administered a questionnaire to family members living with a person with schizophrenia in Morocco. They reported results similar to ours, finding that families in their sample had witnessed many stigmatizing attitudes towards patients and that they sometimes showed discriminatory attitudes themselves.

The incidents of discrimination experienced by patients and their families in the health care arena is particularly worrying. An in-depth analysis of both groups' comments reveals that patients and family members feel that they are often not listened to, not informed, and not taken into account in the decision-making process regarding treatment. Although families and patients mention these experiences as individual discrimination, they should be taken as structural factors: on the one part, professionals and clients alike complain constantly about the lack of time for proper attention. In the end, this short time is mainly used for the patient, leaving just a few moments to work with the families. On the other hand, adequate treatment requires respect for confidentiality, which sometimes results in families feeling that they are not being properly informed. Besides, we must consider the emotional impact on the clinician of working with psychotic patients.

Treating a person with schizophrenia requires an important emotional effort from the mental health worker. Rupture with reality, together with the presence of negative symptoms, forces the clinician into an attitude of directivity and constant active presence in front of the patient, which involves a considerable

expenditure of energy. Communication with families may become an extra effort, which clinicians tend to reduce. Sometimes, the evolution to chronicity, the persistence of symptoms and relapses, causes a real narcissistic injury in clinicians, who experience feelings of guilt and self-devaluation, which increase in front of the patients' families. Often, psychiatrists reasonably assume that the families expect change and, perhaps not so reasonably, that they have a critical attitude towards them for the "ineffectiveness" of their treatment plan.

Health professionals, and particularly mental health clinicians, should pay more attention to their own stigmatizing attitudes towards people with schizophrenia. Those experiences give rise to protective reactions of concealment and isolation, making negative self-concepts possible and having a lasting effect on the outcome of the illness beyond the improvement of symptoms [43]. The therapeutic nihilism in mental health clinicians reported by some of the participants in our study could be related to complex burnout phenomena that may well merit a specific study.

Since this is an exploratory, qualitative study, generalizing the outcomes poses a series of limitations. Sample selection represents the strength of these studies regarding their potential for in-depth description and the generation of new perspectives. However, it also has a weakness: due to the non-random selection and the low number of participants in comparison with quantitative studies, it may not reflect the full scale of the discriminatory experience perceived by the mentally ill and their families. We could also miss some subgroups of patients and family members, particularly the low representation of patients from standard Mental Health Centers on the one hand, and the absence of schizophrenic patients who are not in contact with the Mental Health Network or associations for the mentally ill on the other. The fact that the family groups are mostly made up of women could have a bearing in terms of a heightened perception of discrimination, as suggested by the outcome of a study by Phelan et al. [22]. Through transference and extension, these perceptions of discrimination could be extrapolated to socio-cultural groups similar to the ones in our study.

Results in this study could be useful in helping people with schizophrenia and their families to reflect on the stigma and discrimination they may experience. This could help patients to stop adopting negative stereotypes about themselves, and families to avoid a benevolent or authoritarian attitude, paying more attention to patients' real needs and abilities. One of the different group settings dedicated to persons with schizophrenia and their families could make this reflection possible. Corrigan [39] points to protest, education and contact as the main ways to fight the stigma of schizophrenia. Contact seems to be the more effective means [2]. Educating patients, families, professionals and the public in general may

give rise to an attitude which looks more favorably on contact, lessening the strength of stigma.

Conclusion

Psychiatric patients, and specifically those with schizophrenia, suffer from stigma and discrimination. Experiences of that kind can be found in many areas covering almost all aspects of daily life, including health and psychiatric care. Patients reveal many examples of those experiences and sometimes tend to isolate themselves, perhaps as a defensive reaction to avoid rejection in the social sphere. Relatives witness a great variety of discriminatory situations, and sometimes contribute to such experiences through an over-protective attitude, which may foster the patient's dependency. Besides didactic programs aimed at the public, energetic actions should be implemented to educate patients and their families on the subject, with a view to reducing the reactions that worsen the course of the illness and impede recovery. A special effort should be made to address health professionals in general, and mental health clinicians specifically, who have special needs and exert an important influence on the evolution of the illness. Conveying information of these experiences to the public in general might increase the possibility of contact with persons suffering from the illness, a key factor to modifying social stigma and discrimination.

■ **Acknowledgment** This study has been performed with the support of a grant from the Basque Government's Department of Health.

References

1. Sartorius N (2004) Diminishing the stigma of schizophrenia. *Adv Schizophrenia Clin Psychiatr* 1(2):50–54
2. Schulze B, Richter-Werling M, Matschinger H, Angermeyer MC (2003) Crazy? So What(Effects of a school project on students' Attitudes towards people with Schizophrenia. *Acta Psychiat Scand* 107:142–150
3. Schulze B, Angermeyer MC (2003) Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Soc Sci Med* 56:299–312
4. Angermeyer MC, Matschinger H (2004) The stereotype of Schizophrenia and its impact on discrimination against people with Schizophrenia: results from a representative survey in Germany. *Schizophrenia Bull* 30(4):1049–1061
5. Kadri N, Manoudi F, Berrada S, Moussaoui D (2004) Stigma impact on Moroccan families of patients with Schizophrenia. *Can J Psychiatry* 49(9):625–629
6. Link BG, Phelan JC (2001) Conceptualizing stigma. *Annu Rev Soc* 27:363–385
7. Goffman E (1972) *Internados*. Amorrortu, Buenos Aires
8. Scheff TJ (1966) *Being mentally ill: a sociological theory*. Aldine de Gruyter, New York
9. Allport G (1979) *The nature of prejudice*. Perseus Books, Cambridge

10. Heatherton TF, Kleck RE, Hebl MR, Hull JG (eds) (2000) *The social psychology of stigma*. Guilford Press, New York
11. Guimón J, Fischer W, Sartorius N (1999) The image of madness. *Karger, Basel*
12. Hudson Jones A (1998) Mental illness made Public: ending the stigma? *Lancet* 352:1060–1062
13. McKeon P (1998). Defeating or preventing stigma of mental illness? *Lancet* 352:1942
14. Penn DL (1999) Dispelling the stigma of Schizophrenia: II. The impact of information on dangerousness. *Schizophrenia Bull* 25(3):437–446
15. Boisvert CM, Faust D (1999) Effects of the Label “Schizophrenia” on causal attribution of violence. *Schizophrenia Bull* 25(3):479–491
16. Wahl OF (1999) Mental health consumers’ experience of stigma. *Schizophrenia Bull* 25(3):467–478
17. Sartorius N (1997) Fighting Schizophrenia and its stigma. *Br J Psychiatry* 170:297
18. Sartorius N (1989) Stigma: what can psychiatrists do about It? *Lancet* 352(9133):1058–1059
19. López-Ibor JJ (2000) La lucha contra el estigma de la esquizofrenia. *An R Acad Nac Med* 295–317
20. World Health Organization. *The World Health Report* (2001) *Mental health: new understanding, New Hope*. World Health Organization, 2001
21. Angermeyer MC, Link B, Majcher-Angermeyer A (1987) Stigma perceived by patients attending modern treatment settings. *J Ner Ment Dis* 175:4–11
22. Phelan JC, Bromet EJ, Link BG (1998) Psychiatric illness and family stigma. *Schizophrenia Bull* 24(1):115–126
23. Papadopoulos C, Leavey G, Vincent C (2002) Factors influencing stigma. a comparison of Greek-Cypriot and English attitudes towards mental illness in north London. *Soc Psychiatry Psychiatr Epidemiol* 37(9):430–434
24. Estroff SE, Penn DL, Toporek JR (2004) From stigma to discrimination: an analysis of community efforts to reduce the negative consequences of having a psychiatric disorder and label. *Schizophrenia Bull* 30(3):493–509
25. Link BG, Yang LH, Phelan JC, Collins PY (2004) Measuring mental illness stigma. *Schizophrenia Bull* 30(3):511–541
26. Silverman D (2000). *Doing qualitative research. a practical handbook*. Sage, London
27. Morgan DL (1997) *Focus group as qualitative research*, 2nd edn. London
28. Krueger RA, Casey MA (2000). *Focus groups*. 3rd edn. Sage, Thousand Oaks
29. Morgan DL (1998) *Successful focus groups. advancing the state of the art*. Sage, London
30. Casey MA (1995) Concerns in the analysis of focus group data. *Qual Health Res* 5(4):487–495
31. Morgan DL, Krueger RA (1998) *The focus groups kit*. Sage, London
32. Riley BP, Kendler KS (2005) Schizophrenia: genetics. In: Sadock BJ, Sadock VA (eds) *Kaplan & sadock’s comprehensive textbook of psychiatry*, 8th edn. Lippincott Williams & Wilkins, Philadelphia
33. Pinfold V, Byrne P, Toulmin H (2005) Challenging stigma and discrimination in communities: a focus group study identifying UK mental health service users’ main campaign priorities. *Int J Soc Psychiatry* 51(2):128–138
34. Wahl Ö (1999) Mental health consumers’ experience of stigma. *Schizophrenia Bull* 25(3):467–478
35. Dickerson FB, Sommerville J, Origoni AE, Ringel NB, Parente F (2002) Experiences of stigma among outpatients with Schizophrenia. *Schizophrenia Bull* 28(1):143–155
36. Angermeyer MC, Schulze B (2001) Reducing the stigma of Schizophrenia: understanding the process and options for interventions. *Epidemiol Psychiatr Soc* 10(1):1–5
37. Angermeyer MC, Löffler W, Müller P, Schulze B, Priebe S (2001) Patients’ and relatives’ assessment of Clozapine treatment. *Psychol Med* 31(3):509–517
38. Penn DL, Kohlmaier JR, Corrigan PW (2000) Interpersonal factors contributing to the stigma of Schizophrenia: social skills, perceived attractiveness, and symptoms. *Schizophr Res* 45:37–45
39. Corrigan PW, Markowitz FE, Watson AC (2004) Structural levels of mental illness stigma and discrimination. *Schizophrenia Bull* 30(3):481–491
40. Stout P, Villegas J, Jennings NA (2004) Images of mental illness in the media: identifying gaps in the research. *Schizophrenia Bull* 30(3):543–561
41. Cohen J, Struening EL (1962) Opinions about mental illness in the personnel of two large mental hospitals. *J Abnorm Soc Psychol* 64:349–360
42. Angermeyer MC, Schulze B, Dietrich S (2003) Courtesy stigma. A focus group study of relatives of Schizophrenic patients.. *Soc Psychiatry Psychiatr Epidemiol* 38:593–602
43. Link BG, Struening E, Rahav M, Phelan JC, Nuttbrock L (1997) On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *J Health Soc Behav* 38(6):177–190