

# The Disregarded Caregivers: Subjective Burden in Spouses of Schizophrenia Patients

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## Abstract

Although the burdens of relatives of schizophrenia patients have been the subject of numerous studies, there are hardly any publications on the living situation of the patients' spouses. The findings of this qualitative interview study of 52 spouses of schizophrenia patients are, therefore, especially noteworthy. Spouses not only face illness-specific burdens but also burdens resulting from their partnership and family roles. From a biographical point of view, schizophrenia is often evaluated by the spouse as a decisive point in life that seriously affects the couple's relationship, the family, and the spouse's own life. The chronic burdens of everyday living can profoundly reduce the quality of life and the subject's satisfaction with the partnership. Though partnerships with schizophrenia patients are at risk of breakdown and separation in many respects, they are often maintained for years. Despite the illness-related burdens, many spouses take positive stock of living together. Stable partnerships seem to be achievable when the partner's impairment is perceived as moderate or moderately severe, and when the frequency at which psychotic episodes occur is assessed as still being tolerable. Spouses who suffer from mental illness or impairment themselves often experience the partnership as an appropriate and satisfactory way of life. In these cases, the mutual understanding rooted in the subject's own experiences with the illness is important.

**Keywords:** Schizophrenia, spouses, caregiver burden, family, qualitative research.

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As a result of de-institutionalization and the increasing shift of psychiatric care to the community, the role of family caregivers has gained in importance. Today, after their relatively short stay at inpatient care, most schizophrenia patients are discharged to their homes—in most cases this means back to their families. On the one hand, this devel-

opment represents an immense progress for the patient because natural social integration into the family and partnership cannot be replaced by any psychiatric care service—regardless of how good it may be. On the other hand, living with a schizophrenia patient can put considerable burdens and restrictions on the rest of the family. Since the mid 1950s, researchers have been investigating the effects of mental illness on patients' caregivers. Regarding the impairments and emotional distress that occur as a consequence of schizophrenia, Hoenig and Hamilton (1966) were the first researchers to differentiate between the objective and subjective dimensions of burden: objective burden is defined as the concrete and observable costs to the family that result from the disease, such as financial expenditures and the disruption of everyday life, whereas subjective burden refers to the individual's own assessment of his or her impairments and the extent to which he or she perceives the situation as burdensome. Today numerous studies document a high degree of objective and subjective burden in relatives (Maurin and Boyd 1990; Loukissa 1995; Provencher 1996; Rose 1996; Baronet 1999). At the same time, the results of these studies raise questions as to how much family caregivers can provide assistance to the patients before they themselves become overburdened and require professional help.

Despite the long tradition of caregiver burden studies, hardly any studies up until now have focused on the living situation of spouses of schizophrenia patients. An in-depth analysis of the existing literature revealed that research on relatives of schizophrenia patients has almost exclusively questioned parents of schizophrenia patients, and only rarely the patients' spouses (Jungbauer et al. 2001). This gap in research is even more surprising as there are numerous publications dealing with specific burdens in spousal caregivers of patients with other psychiatric disor-

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ders, such as depression or dementia (Benazon and Coyne 2000; Levkovitz et al. 2000; Bauer et al. 2001). Why have the spouses of schizophrenia patients largely been neglected in previous research? One possible explanation might be a selection effect that occurs when recruiting study participants: for pragmatic and economic reasons, the study participants are usually recruited among the members of self-help groups and caregiver associations, which for the most part are parents (Jones and Jones 1994). The reason why only little attention has been paid to spouses could also be connected with the fact that the family of origin remains the most important social contact for the majority of schizophrenia patients (Angermeyer 1995). Furthermore, many researchers presuppose that only in exceptional cases are schizophrenia patients able to live in a stable partnership, because of the relatively early onset of the illness and the illness-related deficits of the patient (e.g., Johnson 2000).

From the results of studies with schizophrenia patients it can be concluded, however, that marriages and partnerships with schizophrenia patients are more common than has been generally assumed. It is true that many schizophrenia patients actually do not have a spouse and that the relationship with their parents remains the most important long-term social contact. Conversely, on the basis of new longitudinal studies, it can be assumed that approximately 20 to 30 percent (a relatively small but nonetheless significant percentage) of patients live in a partnership, in many cases even for many years (Schulze Mönking et al. 1996; Salokangas 1997; Häfner and an der Heiden 1997). A study with 307 schizophrenia patients in Leipzig, Germany, which was conducted at the same time as the present study, revealed that 32.9 percent of the subjects were married or were living with a partner (Kilian et al. 2001). Apparently, female patients suffering from schizophrenia have better chances of marrying or having a stable partnership than their male counterparts (Stromwall and Robinson 1998; Häfner and an der Heiden 1997). Besides, it is remarkable that patients permanently living with a spouse have, as a rule, an exceedingly positive illness and social prognosis (Schulze Mönking et al. 1996; Salokangas 1997). This finding suggests that patients with a relatively favorable course of illness are more likely to find a spouse and to maintain their partnership; it also appears plausible that an intact (or at least existing) partnership represents a protective factor for the patients' long-term coping with the illness. As Salokangas (1997) has pointed out in this context, positive interactions between the stability of the partnership and the course of the illness, as well as with the coping process, are likely.

From the few studies explicitly investigating spouses of schizophrenia patients, a fragmentary and partly contradictory picture emerges. Hell's study (1982) yielded

that spouses of schizophrenia patients and spouses of depressive patients do not differ regarding their personality structure, neither within their groups nor in comparison to the general population. Illness-specific patterns of relationships (e.g., "typical schizophrenic" relationships) also could not be identified. In both sub-samples, the course of the illness is accompanied by adaptation processes on the part of the spouses that have a normalizing and stabilizing effect on the partnership. On the contrary, in his interview study, Melcop (1997) found that in most of the cases investigated, marriages or partnerships with schizophrenia patients are either not entered into or "almost as a rule" break up during the course of the illness. According to the author's findings, partnerships are, above all, possible with a spouse who is also afflicted with a mental illness and, given this, also have prospects of temporal persistence—an assumption in accordance with the assortative mating hypothesis, which has mainly been discussed in the context of depressive patients' partnerships (e.g., Matthews and Reus 2001). Regarding the spouses' need of support, Mannion et al. (1994) remark that they often do not participate in intervention programs for caregivers because these are mostly tailor-made for the needs of parents and do not sufficiently take account of partnership-specific matters. The authors, therefore, think it necessary to conceptualize and implement specific support offers for spouses.

Considering the fact that spouses of schizophrenia patients have, so far, rarely been investigated, the sample of this exploratory study is unique: 52 spouses of schizophrenia patients were questioned using qualitative interviewing and interpretation techniques. In doing so, the methodical desideratum of more frequently applying qualitative-interpretative methods in psychiatric research was taken up (Rose 1996; Karp and Watts-Roy 1999). As Flick (1997) pointed out, subjective everyday conceptions and biographical interpretations, as manifested in patients' and caregivers' narratives and everyday descriptions, are an important key to understanding their living situations. Qualitative methods of interviewing offer "natural" access to the interpretation of these subjective mind structures and constructions, which would otherwise be blind to systematic questioning (as in standardized interviews or questionnaires).

## Methods

**Subjects.** The study was carried out in Leipzig, Germany, as a part of the larger research project "Health and Financial Burden on Caregivers of Mentally Ill Patients." The study participants were recruited from inpatient, day care, and outpatient psychiatric facilities. First, the psychiatric staffs of the hospitals were asked to

inform those schizophrenia patients living with a spouse of the planned study. Apart from the psychiatric diagnosis, living together in the same household was an additional criterion because it indicates a certain temporal persistence of the relationship. A total of 141 patients fulfilled these criteria for inclusion. On the condition that the patients agreed to their spouses' interviews ( $n = 75$ ), the latter were contacted by telephone or mail. Fifty-two out of the 75 spouses who had been contacted agreed to participate in the study. The sample comprised 28 male and 24 female subjects.

Table 1 summarizes the socio-demographic characteristics of the spouses interviewed. The average age of the interviewed partners was 46; the age span ranged from 22 to 72 years. A survey of the subjects' current or most recent occupations yielded the following distribution: 27 percent of the study participants were workers or skilled workers, 10 percent were self-employed, and 8 percent were still students or in training. Thirty-six percent were semi-skilled and skilled employees (e.g., clerks, service workers, etc.) and 19 percent were employees in more highly qualified occupations or in managerial positions. At the time of the first interview, the spouses had been living with the patients for 15 years on average; 75 percent had children. In 40 percent of the cases, the patient's schizophrenia occurred for the first time during the course of the partnership; in 60 percent of the cases, the illness had already existed when the couple met. Twenty-one percent of the interviewed spouses had a mental illness or had experienced mental impairments themselves when the partnership started. In most of these cases, the couple had met in the context of psychiatric care, e.g., in a psychiatric hospital, in the scope of a career-orientated reintegration measure, or through arrangements made by the psychiatrist in attendance.

The average age of the schizophrenia patients was 45 years (SD 10.9) and most of them had been in psychiatric care for almost 15 years (SD 9.9) at the outset of the study. At the time of their spouses' interview, 87 percent

of the patients received regular outpatient treatment from a registered psychiatrist, 15 percent were in day care, and 8 percent were in inpatient psychiatric treatment (for this question, multiple answers were possible). Most of the patients (72%) received a disability pension at the time of the study. Nineteen percent of the patients were employed, 4 percent were unemployed, and another 4 percent were retired. In order to record the patients' momentary functional impairment, the psychiatrist in attendance was asked to make a quantitative assessment according to Axis V of the *DSM-IV* (Global Assessment of Functioning [GAF]; APA 1994). All psychiatrists involved in this study were trained in conducting such a GAF diagnosis. An average GAF value of 53.5 (SD 12.1) showed a moderately severe impairment.

**Data Collection.** The interviews were conducted by qualified psychologists in the form of home visits. Using a narrative-interview technique, the patients' spouses were questioned regarding the subject of illness-related burden; followup interviews were conducted after 6 and 12 months, respectively. First, the spouses were asked to report about their changed situation as a result of the mental illness ("What has changed for you since your wife's/husband's illness?"). In the followup interviews, the opening question was: "What has happened since our last interview?" In compliance with the nondirective method of narrative interviews, the interviewer intervened and directed as little as possible during the subsequent reports and descriptions. As soon as a topic was completed or longer gaps in the conversation occurred, the spouses were prompted with questions to continue their narration, such as "What occupies you the most at the moment?" and "Was there anything lately that represented an extreme burden for you?" In addition, the interviewer had the option to generate concrete narration and description of situations by means of narrative-deepening questions, especially in cases where the study participant had a strong tendency toward argumentative or abstracting description. On average, the interviews lasted 30 minutes; each interview was tape recorded and transcribed (Sandelowski 1991). Immediately after the interview was conducted, the researcher wrote a contact protocol on the main themes and topics that had been addressed in the conversation. The contact protocol, moreover, contained additional information that had been given by the spouse but had not been recorded, as well as notes on the observations made by the interviewer concerning the interaction and the context of the interview.

During the course of the study, there were only a few dropouts. Thus, a total of 48 interview sets were available to be included in the qualitative development analysis: 40 of these sets included spouses who participated in all

**Table 1. Description of study participants (52 spouses of patients with schizophrenia)**

Female, $n$ (%)	24 (46)
Age, yrs (SD)	46.3 (11.6)
Married to the patient, $n$ (%)	38 (73)
Joint children, $n$ (%)	39 (75)
Duration of partnership, yrs (SD)	15.5 (10.4)
Personal contact, hrs per wk (SD)	49.2 (23.4)
Employed, $n$ (%)	22 (42)
Unemployed, $n$ (%)	9 (17)
Inability to work because of mental disorder, $n$ (%)	11 (21)

three interviews ( $t_0$ ,  $t_1$ , and  $t_2$ ); moreover, there are another 8 interview sets for which a temporal development could be analyzed using two interviews ( $t_0$  and  $t_1$  or  $t_0$  and  $t_2$ , respectively). Four study participants were not willing or not able to continue their participation after the first interview had been conducted.

**Data Analysis.** For the analysis of illness-related burdens and biographical interpretations of the spouses, the qualitative research strategy Grounded Theory was selected (Strauss and Corbin 1998). The methodical procedure consisted of several stages; the tape-recorded interviews were transcribed verbatim. The interviews to be analyzed were selected according to the recommendations of Strauss and Corbin (1998) for a theoretical sampling within data already on hand. The sampling can be described as a two-step process. In the first step, the baseline interviews were subjected to a global analysis by members of the research team. All available data sources were included (interview transcripts, contact protocols, and other contextual information). In the second step, interviews were gradually selected for a detailed interpretative analysis. The sampling was conducted in the scope of a consensus-building discussion (Neuendorf 2002) based on the criteria of *theoretical relevance* and *theoretical saturation* with regard to the question investigated. In more concrete terms, those interviews were selected for analysis in which a rich variety of the various burdens, restrictions to everyday life, and biographical interpretations had been revealed (maximum contrasting). These individual cases served as the starting point for the creation of preliminary categories. In the further course, variations within a category were described (minimum contrasting) and the validity of the categories in similar cases was checked by the research team. The further sampling followed the rule of generating a large spectrum of topic-relevant categories, until no further categories could be generated (theoretical saturation). To this end, 28 baseline interviews were selected from the data pool and analyzed in depth. Furthermore, significant interview quotes illustrating the respective category as concisely as possible were highlighted. Because the criterion of “theoretical saturation” is difficult to define, the members of the research team met regularly during the data analysis phase in a research colloquium. Furthermore, consultations with other colleagues familiar with the method helped to reexamine and recode interview sequences, as well as to define criteria for choosing interviews for the analysis. In this way, a communicative validation of the sampling and the extrapolated results was secured.

The analysis of burden developments during the course of the study was carried out following the method of typological analysis as suggested by Gerhardt (1995).

The interview material was analyzed in several stages, which allowed the creation of descriptive developmental types representing the main trend of changes and developments reported by the study participants. First, development-related individual case descriptions were generated from the interview transcripts, as well as from contact protocols. These descriptions delineate the main emphasis of the interviews with regard to content, as well as the changes apparent during the study. Second, the reconstructed case developments were related to each other following the principle of maximum and minimum contrasting, from which development-related “clusters” became apparent. Finally, the formation of developmental types based on this analysis was again carried out in the scope of the research colloquium; thematic overlaps and unclear classifications were discussed, and a set of seven developmental types was constructed.

## Results

**Onset of the Illness and Subsequent Psychotic Episodes.** Most study participants describe the onset of schizophrenia as an extremely burdening, in fact catastrophic, experience. The psychotic symptoms occurring for the first time are all the more frightening for the spouse of the person affected as they apparently occur absolutely unexpectedly and can, at first, not be classed at all. In this situation, feelings of powerlessness, fear, and despair are often overwhelming. At the beginning, the delusions, catatonic symptoms, or dissocial behavior of the ill can often not be interpreted as an expression of mental illness; at first, the behavior and the symptoms of the spouse remain entirely inexplicable and irrational. In addition, at the time of the onset of the illness, there is a considerable lack of information about available support offers.

Forced assignment to a psychiatric hospital can be accompanied by dramatic incidents. The patient is overpowered by the medical staff, medically “immobilized,” and “taken away,” while the spouse stands by watching helplessly, experiencing agonizing feelings of guilt, shame, and failure. The first impression of psychiatry is marked by shock and deeply disconcerting feelings upon introduction to unfamiliar surroundings—for example, in the face of structural security measures, limited spatial conditions, or severely impaired copatients. In addition, certain treatment measures (e.g., fixation, severe medical sedation, electroconvulsive therapy) are perceived as incomprehensible, inhuman, and humiliating:

“The worst was the first time in the hospital. Above the bed, there was a net. Well, that was really terrible, they almost, well—chained her to the bed, you could say. And there were quite large sleeping halls—I don’t know

how many patients they had there. That was the hospital in D., and it was quite a big shock to me.” (Interview 095; husband of a schizophrenia patient)

When a partnership is entered after the onset of the illness, the spouse of the person affected may not necessarily be aware of the risk of a renewed acute illness phase and cannot anticipate the burdens connected with it. In these cases, the patient is typically only moderately impaired by the schizophrenia, or even not impaired at all, when the partnership is established. Often the spouse knows “in theory” of his/her partner’s mental illness or the risk of a renewed phase of illness; the burdens resulting from a schizophrenic episode, however, are often underestimated. In other cases, the spouse knows of a “nervous breakdown” his/her partner has experienced in the past but does not reckon with a renewed occurrence of the problems. A schizophrenic relapse of a patient whose illness has probably existed for many years is possibly just as burdening for the spouse as a primary onset of the illness in the course of the partnership is in other cases:

“I have married him with his illness, so to speak. He told me that he was mentally ill, well, but I thought things could be worse—now he has somebody standing by him . . . I can cope with this. But then there were phases I just couldn’t manage. When we moved in 1990—well, that was a disaster! The new rooms, he just couldn’t manage all this. Oh well, and then he started to crack up. Then he got undressed in front of the mirror and then he started to move his hips from one side to the next. I’ve never seen this before. And my heart went into my boots.” (Interview 002; wife of schizophrenia patient)

The situation is different when the spouse has had his or her own experiences with schizophrenia or other mental illnesses. On the basis of the psychic crises they have experienced and suffered themselves, it is likely that they are more capable of understanding the patient’s schizophrenic experiences than spouses without equivalent experiences. Therefore, these spouses experience an acute psychotic episode as less threatening. The risk of relapse and the burdens to be expected in case of an episode are often assessed more realistically and can, moreover, be reacted to more appropriately in acute situations of crisis. Although it is likely that in these cases a schizophrenic episode of the patient can put considerable burden on the spouses, such partnerships are less shaken by this than are partnerships in which only one partner is mentally ill:

“I knew that he had the illness when I met him, and because I knew it, his episode wasn’t such a big surprise to me. [Interviewer: He had told you beforehand.] Yes, of course. We met at the BFW [facility promoting occupational reintegration], and you only get this kind of retraining on basis of rehabilitation if you have certain illnesses. And for my part, I knew what was behind this illness.”

(Interview 176; wife of a schizophrenia patient, afflicted with schizophrenia herself)

In the further course of the illness, the spouses of schizophrenia patients experience immensely stressful burdens when a new psychotic episode occurs. Spouses fear relapses because their past experience has taught them that their own possibilities to provide help are limited in this situation. Spouses still find it difficult to deal with the patient and to react in an appropriate way to his or her behavior during an episode. At the same time, these acute burdens are less serious during later episodes than those burdens occurring during the onset of the illness or the first experienced illness phase, respectively. With growing experience and better information, the partners’ abilities to cope with the problems increase. Thus, changes in the partner’s mood and behavior, for instance, can be better classed and interpreted as an early warning sign of a commencing episode. Moreover, the spouses have gained better knowledge for forthcoming illness episodes as to where to turn to for professional help.

### **Everyday Life With a Spouse With Schizophrenia.**

After an acute psychotic episode has ended, new aspects of burden come to the fore. The burdens during illness phases, which are comparatively stable, are often less dramatic than those of other phases but can have a permanent negative effect on the quality of life. Schizophrenia is often experienced as a constant threat hanging over the patient and the patient’s family, a sort of Sword of Damocles. The ill person is scrutinized with anxious worries for symptoms that might indicate a psychotic relapse. This situation entails a permanent state of strain demanding much of the spouse’s strength. In addition, many spouses have to take on additional duties in the partnership and family because of the patient’s reduced strength. Often, this involves unfamiliar, gender-specific tasks, which had been the duty of the patient before his or her illness:

“Well, I had to take on the male role. We renovated the flat. I did all this myself—well, I repapered the wall and all this. He stood there and watched me; he was not too keen to do it and had no interest in doing all this work. I had to re-adapt to family life, to learn that I can handle all this by myself. We’ve got a garden and I had to do everything by myself. I had to see about the car, and he was just not interested in doing anything.” (Interview 171; wife of a schizophrenia patient)

In many cases, the patient is perceived as permanently changed and impaired, because of persisting negative symptoms and/or unwanted side effects of the medication. Showing consideration for the reduced strength and changed needs of the ill often results in the subject cutting back on his or her own needs—for instance, in

regards to mutual activities. The passive, uneventful, everyday life, which is experienced as pleasant or appropriate by many schizophrenia patients, can be very burdening for their spouses. Balancing the different needs is difficult when the spouse thinks it is important that at least part of everyday life and leisure time is spent together. The time spent at home with the patient often means missing out on joint activities (e.g., going for walks, visiting friends, going to the movies, etc.); everyday life in the partnership is experienced as dreary, tiring, and hindering in the long term.

Another frequent burden in everyday life is the increased potential of conflict between the spouses. Following the onset of the illness, some of the spouses feel their ill partners to be moody and solitary, others moaning and contentious or even vicious and aggressive. The conflicts reported by the study participants range from subliminal tensions and ill-tempered disputes to fierce verbal arguments, severe threats, or even violence toward people and property. Particularly in those cases where the ill spouse has a tendency toward aggressive and provoking behavior, dramatic escalations of conflict can arise.

The joint sexuality can be permanently spoiled by the schizophrenia—for instance, if the sexual interest and pleasure of the ill person are repressed by the negative side effects of their medication. In other cases, long-term treatment with neuroleptic drugs causes considerable increase in weight, which can lead the afflicted to feel ugly or no longer desirable; likewise, the spouse may also experience the patient's increase in weight as a reduction of physical attraction. Disturbances of sexuality can increase when the marital atmosphere is characterized by frequent discord, tensions, and dissatisfaction. Continuous conflicts and disturbed communication can lead to emotional alienation between the spouses. In some cases, the couple refrains from having sexual encounters.

Several study participants report a gradual loss of social contacts, for instance when friends and acquaintances withdraw from the patient and his or her family. In other cases, the patients themselves do not spend much energy maintaining contacts because they fear prejudice or lack of understanding from outsiders. Spouses are affected particularly deeply by loss of social contacts if a mutual circle of friends and acquaintances had existed before the onset of schizophrenia. The loss of these contacts is not only experienced as traumatic because of reduced possibilities of communication and support, but also because the couple has lost an important chance to get a positive impression of themselves as a couple while being together with others.

Subjects who were ill themselves not only reported limitations, but also advantages of living together with the

patient. In everyday life, mutual understanding and mutual support—two attributes founded on the spouse's own experiences with a mental illness—are important. Often, certain preferences and needs are shared, for instance, the need for a quiet routine that is undemanding for both spouses. In some cases, almost all of everyday life is spent together and a quasi-“symbiotic” relationship develops, in which the spouses are closely connected with each other and only have a few social contacts with life outside of the marriage. Such an everyday existence can be considered a satisfying way of life and appropriate for the illness:

“I have to show consideration for my wife, she's got the same thing I've got—schizophrenia. Sometimes I notice that she can't take too much. She gets tired easily. [Interviewer: Can you talk a bit about your everyday life?] Oh, we don't do a lot. We rest a lot in our leisure time—that's our way of relaxing. Then we read quite a lot, listen to the radio, and watch TV. [Interviewer: Well, that sounds like a very quiet life.] Quiet, yes. We lead a very quiet life. That's very important to us, I'd say, because we don't get distressed and so on.” (Interview 121; husband of schizophrenia patient, afflicted with schizophrenia himself)

#### Development of Burden Over a Period of 12 Months.

The analysis of followup interviews yielded 7 different developmental types (table 2): 8 of the interviewed spouses reported a high level of burden and 10 reported a low level of burden throughout the interviews. Five study participants experienced increased burdens in the course of the study because of a massive deterioration of the

**Table 2. Development of burden over a period of 12 months**

Developmental Type	Assigned Cases
1. Constantly high level of burden/chronic burden	8
2. Constantly low level of burden	10
3. Deterioration of symptoms; increased burden	5
4. Improvement of symptoms; reduction of burden	7
5. Changing level of burden	3
6. Preeminence of other burdens	11
7. Crisis in partnership during the study	4
Total	48

patient's state or an acute psychotic episode; conversely, with seven study participants a reduction of burden was recorded owing to an improvement of symptoms or a positive development of the patient, respectively. Four of the interviewed spouses reported considerable fluctuations in experiencing the burden during the course of the study. A fluctuating development of burden was usually connected with corresponding fluctuations in the patient's state of health (e.g., with [for the spouse] an alarming deterioration between  $t_0$  and  $t_1$  and a significant recovery following it). With 11 study participants, nonillness-related burdens became preeminent during the course of the study (such as the unemployment of the spouse, a life-threatening illness, or a family dispute). Four of the spouses interviewed experienced a severe crisis in their partnership during the course of the study, with one female study participant separating from the patient.

An analysis of development, therefore, shows a great variability among the interviewed spouses of schizophrenia patients in regards to experiencing burden. About one-third of the cases can be assigned to developmental types characterized by a constantly high, temporarily high, or continuously increased burden during the course of the study. Conversely, for about the same share of spouses, a constantly low level of burden or a reduction of burden associated with the schizophrenia can be described. Analysis of development confirms the close correlation between the patient's illness curve and the spouse's experience of burdens: With a serious deterioration of the patient's state or a psychotic episode of the patient, the spouses experience massive emotional burdens, while an improvement of the patient's state is often accompanied by a noticeable relief (provided that there are no additional burdening factors, which can but do not necessarily have to be associated with the illness). Incidentally, the analysis yielded no disparities between those spouses who had experienced the onset of the illness during the course of the partnership and those who had met the patient when he or she was already ill. Furthermore, there are no differences between female and male spouses regarding the number of developmental types assigned.

### **Separating or Maintaining the Partnership?**

Immediately after the onset of the illness, the spouses show great solidarity with the ill and strongly reject the thought of separation. This solidarity can, however, begin to weaken during the course of the illness when high hopes for the recovery of the patient have to be revised. When the spouses feel that taking care of the patient permanently demands large personal sacrifices and when there are only limited chances of restoring a satisfactory coexistence, thoughts of separation develop. This is particularly true when a spouse is very demanding regarding

his or her "own life" and when he or she considers alternatives to the partnership with the patient to be possible and/or legitimate:

"As a wife, I don't really feel like I have to stay, because I've got my own life and my own ideas for my life. And for me, the adjustment doesn't mean I have to sacrifice my life. Nobody could really ask that of me. And like I said, during really bad times, I thought long and hard about it, about just how much our relationship still makes sense to me. I mean, it's not as if I'm at an age where I could say [ironic intonation] 'Oh well, I've only got a couple more years left, I can put up with some more years.' No, no way, I can't do that!" (Interview 009; wife of a schizophrenia patient)

A continuation of the relationship is also questioned when the partner can no longer cope with the burdens of living together and discovers or fears serious consequences for his or her own health. With frequent and constant psychotic crises and severe impairments in the everyday life of the partnership, the spouses can reach the limits of their strength. The impetus to separate is especially pronounced in the spouse when the patient repeatedly shows signs of violence or threatens to perform violent acts. Living together is, in these cases, characterized by fear and traumatization. Study participants who have maintained the partnership despite such serious chronic burdens described everyday life of the partnership as a downright "marriage of hell." In most of such cases, however, the spouses will probably separate sooner or later:

"There were situations when he said: 'I will take the knife and stab you!' Well, I always took care in the evening or during daytime to make sure that there was no knife around. And for quite a long time we have slept in separate rooms, just because I was so afraid. He had been quite restless at night; he couldn't sleep well and haunted the flat like a ghost. That way I couldn't sleep either and, as I said, I no longer felt like a human being. To cut a long story short, then he went to the psychiatric hospital in D. And that was in November, I believe on the 15th of November '98, and that's when I said I didn't want him back home anymore. Because I was just too scared." (Interview 171; wife of a schizophrenia patient)

On the other hand, many spouses think that a satisfying partnership is possible and also worth living in despite the schizophrenia. This is the case especially with a comparatively favorable course of the illness: When the psychotic episodes occur at relatively large temporal intervals and when the person affected is not perceived as seriously impaired or changed, a partnership is, altogether, assessed as reasonable and manageable. In addition, with an increasing (joint) illness experience, the spouses learn not only to evaluate the illness, but also how to respond to the ill person in an adequate manner. As a result, the schizo-

phrenia is no longer perceived as a major threat to the partnership as it was at the onset of the illness. Even if a redefinition of the partnership is necessary in some areas of living together, the partnership is usually evaluated positively when the core aspects of the partnership—such as mutual affection, respect, and understanding—have not been seriously damaged by the illness. The compromises and concessions regarding personal needs, which necessarily have to be made in everyday life, are not experienced as a serious problem in the partnership as long as there are still enough aspects of the patient's personality intact, which not only allow commonness and communication between the spouses but also a normal life in the partnership:

"I didn't want to lose him, no, because love played a role, and still plays a role, even today. And when he's healthy, he is a good husband to me, a good father to our daughter too, and everything's right between my husband and me anyway—otherwise we wouldn't have got married. And there are so many things we have in common and no, I didn't want that." (Interview 155; wife of a schizophrenia patient)

**Biographical Interpretation and Partnership Concepts.** Many spouses of schizophrenia patients succeed only gradually in integrating the illness into their *own* biographies as an occurrence and everyday reality and in revising the shared perspectives of life. In retrospect, schizophrenia is often assessed as a decisive point in life with far-reaching consequences for the partnership, the family, and the subject's own life:

"The illness has changed him a lot and as a result, also the family, children, myself, and just the whole surroundings. I'm sure it will never be like it has been in the past because his personality has changed with the illness. And sometimes it's quite hard for me and the children to deal with this. Sometimes you're not willing to accept what the illness has done." (Interview 032; wife of a schizophrenia patient)

Some of the interviewed spouses interpreted the schizophrenia as an "emergency," in which a mutual promise of solidarity is kept. The solidarity with the patient is closely connected with traditional social norms regarding marriage and partnership. These norms are often anchored in religious beliefs and go back to the ideal of the insoluble marriage, in which the spouses stay together through good and bad times and are willing to make personal sacrifices for each other and for the marriage. The spouses believe that in the reverse case—e.g., in the case of a serious illness of their own—they could also rely on the patient. Often, it plays an important role for the obligation felt that the partnership has already existed for many years and that the joint experiences and

accomplishments are assessed in a positive way. As a result of the schizophrenia, the partnership can, however, also be reassessed and experienced more consciously as regards its truly essential aspects. For some of the interviewed spouses, their partnership even emerged strengthened from the "test" of the illness. In this case, the illness is interpreted as a meaningful experience in life and can lead the spouse to accept the illness to a certain extent:

"A 'happy marriage' and 'happy hours'—that's easy to say. But when SOMETHING LIKE THIS happens, such bitter hours, that you stand together in these times—that is some kind of ART. Well, to stand together in hard hours, that's a bigger art than somebody saying 'We are happy!' when they only had happy hours and no problems at all." (Interview 155; wife of a schizophrenia patient)

A comparatively small impact on the partnership can be noticed with a complete remission after acute psychotic episodes. Life together renormalizes to a great extent, particularly when the ill can pursue his or her profession or training. Conversely, the partnership has to be partly or completely redefined when the patient is perceived as severely changed or impaired in everyday life. This redefining concerns different areas of the partnership: With regard to intimacy and familiarity between the spouses, it is important how far the patient is still able to meet the needs of the spouse. Apart from this, the changed needs of both spouses regarding closeness and distance are of importance. Changes also occur with regard to joint activities and interests, with the range of situations spent together clearly being constricted. Furthermore, the responsibilities in partnership and family have to be rearranged in many cases. In particular, this reorganization of duties concerns employment, housekeeping, and parenting—with the patient's spouse normally assuming additional areas of responsibility. The original role allocation in the partnership must shift greatly when the patient is increasingly experienced as dependent and helpless:

"In a way, I have a third child now and he's a very headstrong child. One who is more unpredictable than children usually are and who is also very hard to influence, of course, because the child is really an adult. I don't want to assume the role of the mother, but somehow I have to. Then sometimes this is too much for me. You are the person who takes care of everything, who is there, who has unlimited strength." (Interview 009; wife of a schizophrenia patient)

In contrast, spouses who are themselves mentally ill or impaired often do not experience such fundamental changes in their partnership. Here, the spouse's own illness is a basis for more modest or more realistic wishes in regards to the partner, and the relationship with a partner who is also mentally ill is seen as a chance to live in a partnership at all. When defining the partnership in these



marriages, more emphasis is given to the positive aspects of living together. Here, often a matching of mutual needs and expectations is perceived. The patient is accepted, respected, and tolerated by the spouse as a person who suffers too, often the special kind of understanding resting on the spouse's own experiences with the illness is emphasized. Generally, these spouses refrain from having children together as they are aware that they probably could not manage the tasks connected to parenting. However, there are couples that, despite their handicap, decide to have children, not least because they want to add normality and sense to their lives, which have been shaken by the illness. This can, however, cause serious medium- and long-term problems. If both partners experience an acute illness phase at the same time, the spouses' parents or brothers and sisters will have to help out in order to guarantee care for the children; in other cases, official authorities (e.g., youth welfare office) will have to be called in.

## Discussion

The findings of this study deserve special attention insofar as caregiver burden research has hitherto almost exclusively investigated parents of schizophrenia patients. On the one hand, this trend indicates that spouses of schizophrenia patients are faced with illness-specific burdens that parents and other close relatives might experience in a similar way (e.g., alternation between acute and chronic burdening situations, enduring fears of relapse, changes to the patient's personality). On the other hand, it is obvious that burdens experienced by spouses differ from those experienced by parents in many respects: At the center of the spouses' problems are those relating to the partnership—such as challenging marital intimacy and commonality, reorganization of familial and partnership tasks, and redefinition of plans for mutual life. For parents of schizophrenia patients, on the other hand, other problems and worries regarding the parent-child relation are of importance, such as the question of possibly being responsible for the illness because of poor parenting, the problem of a delayed or prevented detachment from the parents, and the dilemma of a permanent, possibly lifelong dependency of the patient (Jungbauer and Angermeyer 2002). In addition, a marital partnership is usually defined on different grounds than other close familial relationships; while the relationship between parents and grown-up children is often perceived as an indissoluble, lifelong connection, marriage or partnership is interpreted as a relationship that is based on certain conditions and expectations and that can, under some circumstances, be terminated.

The results of this study support the hypothesis that partnerships with schizophrenia patients are possible,

especially in cases where the patient suffers only moderate or moderately severe impairment to his or her everyday life; on the contrary, patients with severe functional impairments and deficits only rarely seem to live in long-term partnerships (though our sample includes such cases). Conversely, it can be supposed that a partnership that is experienced positively represents a stabilizing factor for managing everyday life and the patient's illness. This trend also—and above all—applies to partnerships between two mentally ill patients; for spouses who are mentally ill themselves, the partnership with a person with schizophrenia can represent (for the individual) an appropriate and helpful way of life. Not only the mutual support but also the feeling of having found a “place in life” and having reached some kind of normality are reasons why spouses are, relatively speaking, very satisfied with the partnership.

There is much evidence in favor of the notion that partnerships with schizophrenia patients are a modern phenomenon that is made possible in the first place by improved treatment and support resources for mentally ill people. Social-cultural processes of modernization leading to a *modernization of schizophrenia* may also be of significance (Zaumseil and Leferink 1997); even though prejudices and resentment against mentally ill people are still widespread among the general population (see Angermeyer and Matschinger 1997), the schizophrenia illness is often interpreted differently nowadays than it was some decades ago. This modernization may be more advanced in a city like Leipzig than in more rural regions; moreover, ill persons may have better chances of meeting a suitable partner in urban areas than they would in a rural environment, despite their handicap of mental illness.

When interpreting the results of this study, it has to be taken into consideration that the spouses interviewed were not recruited via caregiver associations or organized relatives' groups, but via patients of psychiatric facilities. Even though this procedure had the advantage that not only spouses with an above-average engagement were asked to participate, there are likely to be other selection effects. First, many spouses could not be interviewed because the patient refused approval for participation. This applied to almost half of the married patients in our study. It is possible that this tended to concern patients who are particularly distrustful or severely affected and whose relationship with their spouses is full of conflict. Because of this trend, it is likely that especially highly burdened spouses were not interviewed in this study. Furthermore, with regard to the documented development of burden over a period of 12 months, it should be considered that the study participants were recruited from treatment sites. This situation presents a possible danger of bias because an acute episode coinciding with stationary

care often constitutes a highly stressful experience that is likely to be followed by a reduction of burden—a situation that will probably not be shared by all spouses of schizophrenia patients.

At this point, it may be also useful to comment on theoretical and methodological issues that have to be taken into account for the classification of the results of this study. Due to the qualitative design of this research, the analyzed interviews were not selected according to the criterion of statistical representativeness. While quantitative research designs are based on the formation of randomly selected and representative samples, the cases in this study were selected following the principle of theoretical sampling (Strauss and Corbin 1990), i.e., according to their relevance for the phenomenon we were interested in. It is also necessary to consider that within the scope of the interview, the study participants were largely free to set thematic priorities. The advantageous aspect of this procedure—to primarily record themes and relationships that are of high subjective importance—is opposed by the fact that the respondents were not directly asked about certain aspects of burden. Therefore, we deliberately refrained from indicating the frequency of the different aspects of spousal burden. This study aimed at an understanding interpretation of conditions and connections in line with Karl Jaspers: “Comprehensible correlations . . . are not proved by numbers, but by understanding the individual case—numbers just show the frequency of their occurrence” (Jaspers 1972, p. 598).

From a clinical point of view, the present findings underline the necessity of putting more emphasis on partnership-specific issues when planning support offers for relatives. Therefore, we strongly agree with Mannion et al.’s (1994) recommendation of specific group offers for spouses of schizophrenia patients. Some important themes that should be considered when preparing support offers for spouses are possible changes in the relationship between the spouses and the patients, problems arising when organizing family and household, and questions of parenting and possible developmental risks as well as possible impairments to sexuality. The spouses should be given enough opportunity to speak about the possibilities of a partnership in spite of the schizophrenia, but also about possible thoughts of separation. Exchanging experiences in a group should be given enough room as it represents an important opportunity for the spouses to class their own problems in relative terms and to find emotional relief. The dialogue with other spouses can, for instance, motivate to reconsider personal attitudes, moral concepts, and perspectives for the future. Furthermore, the group offers opportunities to soothe feelings of loneliness, to establish contacts with other spouses, and to initiate mutual help. This may be of special significance for par-

ticipants who experience loss of social contacts in connection with their partner’s schizophrenia.

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