

## Experience of courtesy stigma among relatives of individuals with schizophrenia – a qualitative study

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### Summary

**Aim.** The aim of the study was to describe the experience of stigma as experienced by individuals accompanying their relatives with schizophrenia in Poland.

**Method.** Four qualitative techniques were triangulated in the study: participant observation, content analysis, expert-interviews, and in-depth interviews. Collected data were analyzed in accordance with M.B. Miles and A.M. Huberman's model.

**Results.** Development of schizophrenia in a family member poses a risk for his/hers family caregivers to enter 'the zone of stigma'. They encounter a discursive invisibility of the mental health problems as well as missing comprehension and empathy. The stereotype-based social grid of convictions about schizophrenia, psychiatry and the lack of social clues of how to proceed, lead to the development of caregivers' sense of constant uncertainty and feeling lost. The common misconceptions about mental disorders create a greater distance and reluctance between caregivers and their distant relatives, neighbors and friends. The prevalence of the disadvantageous discourse on mental illness stimulates the relatives' anticipation of exclusion, evokes shame. Relatives often experience reluctance in their contact with psychiatric staff, ignorance of their needs and as well as professionals' therapeutic pessimism. Such components of 'the zone of stigma' pose a threat to the realization of what is at stake for family caregivers, and give way to their powerlessness.

**Conclusions.** This article presents the results of the first qualitative study on the phenomenon conducted in Poland and characterizes the impact of stigmatizing character of schizophrenia on lives of afflicted individual's family caregivers. In-depth comprehension of the social context of accompanying a relative is crucial for addressing family caregivers' needs in a better way and developing models of cooperation between psychiatric staff and patient's family.

**Key words:** stigma, caregivers, schizophrenia

## Introduction

Among mental health stigma-related concepts such as public stigma, provider-based stigma, structural stigma or self-stigma, courtesy stigma prevails the least explored one [1–3]. Erving Goffman, in his seminal work on stigma from 1963, described that the strength of the stigmatizing attribute might be so penetrating that it taints not only the social identity of stigma bearer but also of those who are associated with them, i.e., in the structure of kinship [4]. The existing body of research on courtesy stigma describes the phenomena in the context of the USA and Western European countries, mostly at the turn of the 21<sup>st</sup> century [5–9]. Available meta-analysis showed that 20–50% of family caregivers admitted experiencing stigma because of the mental health conditions of their relatives [7]. Qualitative studies carried out in the USA describe that what relatives go through is similar to what individuals with mental disorders experience themselves: rejection, devaluation, disappointment and shame [8]. German qualitative works underline that mental illness of a relative is associated with blame, social exclusion, financial burden, discrimination in respect to bureaucratic procedures, and problems with health insurance [9]. Experience of courtesy stigma is associated with objective and subjective burden and generates a tendency to conceal observed difficulties or isolate. Consequently, it may delay starting treatment by a relative, getting support by caregivers or weakening family resources [10–12].

To our best knowledge, no in-depth studies have been conducted to describe the experience of family caregivers in the context of Polish societies. Due to courtesy stigma consequences depicted in the literature, addressing this research gap appears to be crucial for understanding the family caregivers' situation and improving their quality of life.

## Material and methods

In order to reach the goal of reconstructing the subjective experience of courtesy stigma among relatives accompanying their close ones with schizophrenia in Poland, we triangulated reactive and non-reactive qualitative methods. Firstly, we conducted a participant observation in a support group for families of individuals with mental illness in a large Polish city (with a population over 250,000 people) in the years 2012–2014. The aim of this part of the study was to verify the theoretical assumptions, obtain a broad perspective on the research setting, establish trustful relationships with informants and potential interviewees as well as develop research tools for further parts of the study. Secondly, we conducted content analysis of 28 testimonies of family caregivers published between 2007–2015 in a Polish magazine for families of mentally ill individuals. Next, in the years 2014–2016 we conducted expert-interviews with 9 professionals closely related to psychiatric services and cooperating with patients' families in two large cities. As the last stage, we carried out in-depth interviews with 11 family caregivers involved in family organizations from four cities, two with a population up to 250,000 inhabitants and two with

a population over 250,000 inhabitants. We sampled the study participants for professional and individual interviews purposefully until the theoretical concepts had become saturated.

The inclusion criteria for the expert interviews were: an outstanding professional practice in supporting caregivers in one of the following disciplines: psychiatry, therapy, social services, and non-governmental organizations. The inclusion criteria for participation in the in-depth interviews were as follows: a relation of kinship to an individual diagnosed and treated for schizophrenia, participation in any form of organizational engagement in non-governmental organizations dedicated to mental health, living in a medium or large Polish city. Two strategies were applied to sample family caregivers: four of them participated in the support group in which we conducted participant observation, the rest was recruited thanks to contacts suggested by our informants (experts and other caregivers). Among those invited to the in-depth interview, two mothers of individuals with schizophrenia refused participating without providing us with any explanation. Table 1 presents the characteristics of the study participants.

All interviews were conducted according to the interview scenario, audio-recorded and transcribed *verbatim*. The iterative analysis covered the following steps: data immersion, inductive coding, inter and intra-case comparisons, reducing data and visualizing patterns, formulating themes and concepts and was performed using MaxQda12 software [13]. To ensure the high quality of the study at all stages, we incorporated four widely accepted methodological strategies to achieve rigor: the triangulation of multiple data sources and methods, grounded inference, negative case sampling and reflexivity [14]. Due to the specificity of qualitative methodology (study aim, non-probabilistic sampling, applied research methods), results presented in the study should be understood in regard to the study participants. Our result transferability is limited to family caregivers living in a similar social context to the one where our study was carried out [15]. The study was approved by the Ethics Committee of the Institute of Sociology of the Jagiellonian University in Krakow.

## Results

The analysis enabled us to describe the ‘zone of stigma’ which is designated by relatives’ perceptions and their daily experiences in various social domains, which may have transformed or emerged due to development of mental disorder of their next-of-kin. Basing on the gathered data, we depicted the following components of ‘zone of stigma’: the disadvantageous discourse, the great unknown, lack of social clues, apathy of the healthcare system, reluctance in psychiatry, endangered what is at stake, distanced relations, triangle of stigma, powerlessness. Figure 1 visualizes those components as well as their internal relations. The following sections elaborate on each of them.

### The disadvantageous discourse

A large part of the stigma experienced by caregivers is the social invisibility of the needs of people afflicted with this illness and their families. Relatives encounter a discursive absence of the matter and missing comprehension and empathy of their situation in most social circles. Relatives described that people in their surroundings often do not understand their situation or that they repeatedly felt they were not being understood. One of the mothers regretted not being able to discuss her worries regarding her adult child's mental disorder with any of her friends: "I don't have friends who I know would understand. Because they would just say 'yeah, yeah', and that's all. But then turn away..." (C\_8). Moreover, relatives perceive a dominance of ignorance towards the needs of individuals with mental illness in a number of state institutions, i.e., in local city halls or in courts. Both, family caregivers and experts often discussed the issue of the commonness of a lack of mental health awareness. The interviewed professionals and relatives talked about six categories of stereotypes: (1) dangerousness of the mentally ill, (2) unpredictability, (3) otherness, (4) schizophrenogenicity, (5) opposing mental illness to somatic diseases, and (6) incurability, that typically are applied by the public to individuals with mental disorders, their family caregivers and psychiatry. The significance of the last one is fundamental when trying to understand caregivers' situation as it determines making treatment efforts.

Table 1. Characteristics of study participants: authors of written testimonies, professionals and family caregivers

Authors of testimonies			Professionals			Family caregivers					
author's code	sex	relation to IMD	expert's code	sex	field of professional experience	years of professional experience	caregiver's code	sex	relation to IMD	years of care	Place of residence
A_1			E_1	F	social worker; local integration projects for families of IMD	25	C_1	F	child	15	L.C.
A_2			E_2	F	social worker; local integration projects for families of IMD	5	C_2	F	parent	15	L.C.
A_3			E_3	M	psychologist, psychotherapist; psychoeducational programs for relatives of IMD	20	C_3	F	parent	14	L.C.
A_4			E_4	F	psychologist, psychotherapist; psychoeducational programs for relatives of IMD	10	C_4	F	parent	16	L.C.
A_5			E_5	M	community psychiatrist; psychoeducational programs for relatives of IMD	15	C_5	M	parent	16	L.C.
A_6			E_6	M	community psychiatrist	30	C_6	F	parent	12	M.C.
A_7			E_7	F	community psychiatrist; psychoeducational programs for relatives of IMD	10	C_7	F	parent	15	M.C.
A_8			E_8	M	psychiatrist; psychotherapy	40	C_8	F	siblings	23	M.C.
A_9			E_9	F	local NGO for families of IMD	10	C_9	F	parent	25	M.C.
A_10							C_10	F	parent	11	L.C.
A_11							C_11	F	parent	23	M.C.
A_12											
A_13											
A_14											
A_15											
A_16	M	parent									
A_17											
A_18	F	child									
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IMD – an individual with mental disorder; L.C. – a large city (over 250,000 inhabitants);

M.C. – a medium city (100,000–249,000 inhabitants)



psychiatric department. The newspaper focused its reporting on the negative comments of other patients at the hospital, who felt threatened by the psychiatric department and demanded the expulsion of the patients from the psychiatric ward. The interviewee was furious with the newspaper editor. She found the decision to publish the article was disadvantageous for the system of mental health care in her city. She felt the media should be ready to engage in changing the negative attitudes towards mental health, rather than reproducing fears and hatred towards individuals with mental problems.

The merging of stigmatized meanings into language also contributes to the disadvantageous discourse. One interviewed psychiatrist coined a term for them: “the words of shame” (E\_8) and explained that the meanings ascribed to the locally recognized names of those institutions serve to transmit excluding semantics, which can significantly impact the experiences of individuals afflicted with mental illnesses and their families. This observation was reflected in caregivers’ narrations.

### The great unknown and lack of social clues

The gathered material suggests that the discourse about mental disorders in Poland lacks constructive narrations based on facts and easily accessible by lay people. The disadvantageous discourse leaves family caregivers with unreliable representation of schizophrenia and determine a caregivers’ sense of the great unknown – their lack of knowledge and a lack of comprehension about what is happening with a relative. Symptoms of mental problems are commonly perceived as out of the range of evident health difficulties everybody should be able to recognize and adequately react to. One mother wrote: “At that time I didn’t understand my son’s illness, I didn’t know what was happening to him” (A\_12). None of the available cognitive schemas provide a reasonable solution. The change in a relative’s functioning was, in most cases, rationalized with more familiar explanations, e.g., developmental or contextual causes.

Similarly to Patricia Howard’s study on maternal caregiving experiences, in which groping for information was the repeated experience of mothers caring for adult children with schizophrenia [16], searching for information about mental illness and trying to understand mental illness emerged as one of the greatest challenges for relatives also in the narratives of Polish caregivers. As the majority of study participants had more than a decade of experience caring for their close one, their experiences need to be understood in the context of the social awareness prior to any anti-stigma campaign and of a much less digitized world. Nevertheless, being among relatives attending the support group for the first time in years 2012–2014, we also met people with a shorter experience of accompanying a mentally ill relative who potentially had greater access to information about the illness and experienced the sense of being lost and helpless, as families with more long-term experience remembered when looking back at the initial years. It suggest that despite the availability of information about mental disorders is definitely higher today than even just a decade earlier, the experiences of the study participants indicate that the satisfaction of the need to understand the close one’s condition continues to be rather low. The emotional tension, a result of the cognitive struggle to grasp the problem, is at the very core of the sense of being lost and confused. Moreover, family

caregivers' struggles are amplified due to a lack of social clues defining how to manage the unclear situation. One of the authors of the accounts wrote:

*I have a son afflicted with schizophrenia and from my experience I know that many parents and caregivers when encountering mental illness for the first time desperately seek for solutions of the problem and some help. (A\_23)*

The taboo of mental illness hinders the development of a socially available scenario to guide the relatives of an afflicted individual during the psychotic crisis. The lack of common practices makes the process of determining a pathway of support challenging. Not being equipped with a pattern of action, relatives employ methods of trial and error when looking for intuitive solutions. It is accompanied by a dominating sense of constant uncertainty and worries about an ill relative, which proves there to be a lack of social regulation that could clearly guide individuals through the situation of a family member's psychosis. A social worker explained the experience of disorientation in family caregivers based on her long-term professional experience:

*[...] at some point the symptoms are clear and there are no doubts, that it is mental illness. Parents are completely helpless because in every illness it's obvious how to cope, how to treat, it's clear you need a doctor, he'll prescribe medications, the ill goes to bed, takes the pills systematically, and it's getting better. In the case of mental illness, on the other hand, especially in the case of schizophrenia, it is not known what to do. Mental illness refers to thinking, feelings, senses, so those characteristics which are individual to everybody. And so families in this situation they don't really know how to cope. First, they ask the relatives [to change], they try to solve the problem, they make efforts to build a bound and impact the ill. In the most cases it doesn't work. Later they start to get angry, it doesn't help either. Then maybe some other ways, but nothing really helps, or even makes the situation worse. And then they simply don't know what they should do next. (E\_1)*

The material obtained by triangulation of data sources indicates that the lack of understanding of relative's distinct behavior triggers stress, fear and a sense of helplessness. Confusion continues in regard to searching for help. Not knowing how and where to find any form of support becomes a barrier that prevents families from getting help, sometimes for a long time.

At various points in my study this sense of insecurity of the situation was voiced. Its apparent component is the high intensity and frequency of worry. Relatives' worries concern a number of aspects, including: concerns about the future of the ill relative and the stability of his/her recovery, about caregivers' own life, and concerns about other relatives. Decisions about relatives' psychiatric hospitalization, involuntary placement and involuntary treatment, incapacitation were also described by a number of relatives as tough decisions. One account outlined the difficulties experienced by many relatives of individuals with schizophrenia:

*He [the ill family member] doesn't want to get treatment, denies the illness, behaves aggressively. A family has a dilemma, whether to go to court and apply for coercive treatment; [the family members] have remorse when they led to its implementation, they are not fully convinced whether they took the right steps. (A\_14)*

As suggested by the experience of the participants of this study, most relatives felt left alone with solving this dilemma.

### Distanced relations

The gathered accounts of relatives suggest that family members experience various forms of exclusion: reservation in direct interactions, or reluctance to provide informal help in closer and more distant social relations. Some relatives share with us their resentment that their local communities express the need for isolation of individuals with mental illness, or removing them from common spaces. The caregivers talked about the lack of interest or reluctance of their other relatives and acquaintances to be contacted. Often it caused feelings of disappointment and a sense of abandonment. An interviewee's (C\_7) only brother turned his back to her when she asked him for help with her son who started showing alarming behavior. Mental health problems are perceived as otherness, and therefore attracts prying looks, and become topic of gossip. One of the interviewed mothers (C\_2) at some point realized her family situation was circulating in her local community as gossip and decided to withdraw from those contacts.

### Apathy of the health care system and the reluctance in psychiatry

The gathered material exposed the subjective perspective on the phenomenon of provider-based stigma and structural discrimination, described in other cultural contexts [17, 18]. The caregivers shared their experience of numerous challenges in contacting psychiatric staff and their regular disappointment when communicating with professionals showing reluctance. What our data reveals is the big extent of the paternalism that structures relations between professionals and patients' families. The relatives' experiences regarding contact with psychiatry professionals included: psychiatric staff overlooking families' needs for information and support, disrespectful attitudes, as well as restricting contact between the patient and his/her family. Professionals that our respondents had to deal with often disregarded observations of family caregivers. Families felt that their observations of how a patient changed, how he/she responded to medications, what his/her lifestyle was should be valuable sources of information for the psychiatrist.

A number of our interviewees felt resentment towards the psychiatrist diagnosing their close ones, who neither explained the symptoms of schizophrenia nor gave guidance on how to cope with it. In a great deal of relatives' experiences, there were concerns arising from not obtaining information about the health status of a family member during or after his/her hospitalization. This tendency of ignoring relatives'

points of view was particularly alienating. One of the participants felt that in the doctors' eyes the observations she made on the functioning of her mother were invalid:

*We are treated as objects, we are ignored. Many times, still as a young person, they talked to me with tongue in cheek, my opinion wasn't taken into account seriously. (C\_1)*

Another interviewee recalled his impression that “no [family's] perspective was taken into account, never, caregivers completely don't count, their situation is unknown, unwritten, not asked about, which means it is invalid” (O\_5). Some psychiatrists' lack of interest or even open reluctance toward families' engagement gives the impression that relatives are excluded from the circle of people involved in an individual's recovery. The gathered material suggests that some professionals' views on patient's relatives might refer to the out-dated belief of schizophrenogenicity. On various occasions some relatives mentioned incidents of feeling being judged or blamed by psychiatric staff. One of the interviewed mothers went to the psychiatrist when she first noticed the alarming behavior of her son. What she heard from the psychiatrist was that it was her parental fault that her child behaved aggressively. The mother was shocked after the consultation: “You brought up your son like that, now you need to harvest the crops' –the doctor said directly... And she didn't even prescribe any tranquilizers!” (C\_9). Another stereotypes determining professionals' reluctance towards relatives might be the conviction of relatives being obtrusive. One psychiatrist underlined the extent to which most professionals regard the significance of families in the process of treatment as being poor. She explained that referring to medical confidentiality in response to relatives' requests for information is a strategy to avoid contact with patient's relatives:

*[...] hiding behind the medical confidentiality is so that the doctor doesn't have to talk with a family about the difficult topics. Family is treated only as a source of an environmental interview and seen as claimant. [Doctors] have a feeling that the family is taking much time, that family is demanding, shifting their various difficulties to these people, and at the same time it is required that everything should work faster, shorter and according to some pattern. (E\_7)*

From the caregivers' narratives emerged a particular manifestation of stigma. Families experienced on various occasions the dramatic dominance of negative views of the chances of recovery, and of the better functioning of individuals with schizophrenia among psychiatric staff. Therapeutic pessimism corresponds with the disadvantageous discourse on mental illness especially with the stereotype of schizophrenia being incurable as well as with the conviction that individuals with schizophrenia are socially useless. Receiving the suggestion of their close ones' incurability was remembered by many caregivers as profoundly stressful. One of the mothers heard from an attending psychiatrist that there was no chance for her son's recovery.

*[...] Once a doctor said to me directly: “What do you expect? Your son has been 12 times in hospital so far, he is 28 years old, he should be living in a long-term care facility by now”. I replied: “What do*

*you mean?”. “Yes, this process will not work”. (laughs) You can say he wanted a life-sentence for him, and send him to LTCF. I was shocked. (C\_10)*

The collected material also showed that family caregivers also encounter institutional apathy, especially troubling in the fields of healthcare and social services. The low quality of psychiatric care is manifested not only in poor infrastructure (i.e., crowded psychiatric wards, lack of staff and a limited offer of therapeutic treatments available to patients in psychiatric facilities) or little support offered to the relatives, it is also exhibited in the inadequate care of any somatic health problems for patients in psychiatric wards. Facing the inability to cure an ill family member adds to the stress, anger and fears of caregivers.

Moreover, some relatives emphasized the negligent attitude of some psychiatrists towards their afflicted close ones. They felt that some of the specialists approach patients with little attention and base their work on superficial schemas. Those of the study participants who accompanied their close ones to various psychiatric care facilities were critical of the common practices of depersonalizing patients with mental disorders. Finally, the collected data suggest that providing education and information for families is rare in these facilities. Professionals remarked that the support offered to family caregivers is changing and varies between hospitals. A professional we spoke to, who had years-long experience of organizing forms of support for relatives, explained that the barriers of access to support are the result of a lack of legal solutions in the healthcare system, too few professionals specializing in working with families, as well as bureaucratic restrictions:

*Structural conditions also overlap, except for this barrier resulting from stigmatization, these structural formal and legal conditions of support for families are so pushed away, and the public healthcare is organized so that time for the family is limited or not all centers offer specialized family therapy or you have to go into the procedure, and they need something between, I don't know, a psychotherapeutic visit and family session. They simply need a normal conversation, and that can't be contracted. (E\_9).*

Professional help available in support groups is offered by a narrow **circle of clinicians, including psychologists and psychiatrists who cooperate with NGOs** that finance meetings for families.

This institutional apathy and reluctance of psychiatry are associated with the disadvantageous discourse, which determines the low priority of mental health and therefore low funding of psychiatry in Poland. These two components of structurally embedded stigma manifest themselves in most dimensions of psychiatry as experienced by families of individuals with schizophrenia.

#### Endangered what is at stake

Many relatives in their narrations referred to what is at stake to them but due to schizophrenia-related stigma is endangered [19]. The recurring values mentioned were:

afflicted relative's self-dependence and occupation, hope and realization of the parental role. Envisioning their own death and thus leaving a child unable to fully manage their life was indicated as challenging for the majority of parents. Those whose only child was ill worried that the child would have to stay in a long-term care facility, something they regarded as a negative scenario. Furthermore, relatives were concerned about their close ones' passivity, lack of a sense of purpose, daily boredom resulting from the lack of opportunities to be involved in any organized activity, insufficient or inadequate opportunities for rehabilitation, permanent unemployment and poor chances of getting a job. Interviewees interpreted them as posing risks to his/her self-growth and also threatening their existence.

Furthermore, a considerable number of family caregivers brought up the notion of hope and its significance when accompanying an ill relative, as well as for the affected individuals themselves. Most relatives indicated hope as a desired attitude that motivated them to undertake actions to enhance a relative's health situation. On the other hand, in the context of the commonly-held belief that schizophrenia is incurable, relatives perceive hope as an endangered burden to their efforts for optimism and faith in the better functioning of their close ones.

The final concern were threats of not being able to realize the maternal role and fulfilling assigned obligations, such as setting an example to a child, accompanying and being there, or fulfilling the basic needs of the ill child. A number of support group participants talked about their frustration and powerlessness associated with the hospitalization of an adult child, including his/her right to refuse to inform the family about his/her health condition and the resulting stress of relatives who are refused information and/or visit. Another challenge from the perspective of experiencing the parental role was the parent's decision about involuntary treatment. One mother shared her fears about taking such a step:

*And this is it (breath-out). Unfortunately, you have to overcome the fact that you have to send your son to hospital... The first time they had to tie him up, but he also explained to himself that he did not want all this, neither injection nor binding, and this is a necessity at such a moment [...]. When you go to the hospital and you see these different cases of these illnesses... Well, you do not need this shame and you send this son. Somehow I remember some woman said: "Unfortunately, you should send [your child] to hospital". And when a doctor told me: "You have to send him to hospital, otherwise we won't be able to manage him. He must be in treatment", well, a mother's heart says something else, but actually you need to send this son or daughter to hospital. So that they could give him an injection, to restrain him, in the first phase. (C\_3)*

Sense of competence among caregivers is endangered by the socially embedded idea of mother's guilt manifested by a sense of being overtly accused of 'bad mothering' or being ignored by medical staff, as well as by the effects of structural discrimination hindering the ill person's independence, i.e., poor quality treatment, a lack of opportunities for rehabilitation or sheltered employment, and uncertainty of social benefits.

### Triangle of stigma

Analysis of the obtained material allowed us to determine that the theme of the subjective experience of courtesy stigma are interdependent anticipation, shame and secrecy. The first component covers relatives' expectations of experiencing adverse social reactions, being rejected, treated badly, or an ill relative losing their job. The anticipation arises in two situations. Firstly, when a relative notices the disadvantageous discourse and feels its threatening characteristics towards their family identity. The second situation comes about when the family experiences prejudicial or hostile behaviors due to the relative's health condition. The first situation is based on the fear of an undefined hypothetical response of the environment when the relative's illness comes to light, while the second one is based on previous exclusion experiences.

Analysis of the collected data is consistent with the theoretical assumptions made by Goffman [4] – that shame is at the heart of the courtesy stigma experience. One of the interviewed mothers perceived it as follows:

*[...] there is this the conviction in Poland that a person with a mental illness brings shame to the family, then apparently it is a pathological family because only in pathological families mental illness can occur. That's what people really think, that it is simply shame and it's better not to talk about it. I think it has been existing in the society for years now. (C\_10)*

All professionals perceive shame as a dominant experience among family caregivers. One of the psychologists moderating support groups recalled cases of relatives preferring to stay in one-to-one contact with her and refusing to participate in group meetings. Talking about one particular family, she said:

*Arranging a meeting always comes after we have negotiated that I will visit them in their home. They feel that, because the institution here is so specific, somebody might see them (E\_4).*

For many caregivers, secrecy seems to be a solution for the tension that arises from anticipation of rejection and strong feelings of shame as a result of the ill relative's non-normative behavior. As relatives' narrations and professionals' observations suggest, the concealment is aimed at hiding the information from all those who do not constitute immediate relatives, i.e., more distant relatives, neighbors, acquaintances, work-colleagues or strangers.

*[...] not that rarely it happens that only the closest ones know about the mental illness. And sporadically it happens that this fact is known to a greater group. (E\_3)*

Secrecy determines relatives' daily life, decisions related to treatment of the ill relative and sometimes leads to great life decisions. As in the case of one of the mothers, who to avoid anticipated adverse reactions of the neighbors, who knew her son as a successful person from before the development of his psychotic disorder, she decided to move away from the neighborhood.

*[...] we disappeared from this neighborhood, in which he was known before as a normal, nice guy. [...] How he would find himself in this environment? It was simply completely impossible. So we managed with all, it was obviously a big thing to (inhales deeply) move the things etc., but we managed it. (R\_7)*

### Powerlessness

Experiencing this web of circumstances impacts family caregivers' positions and may give way to powerlessness, comprising a sense of helplessness, losing control over family life, feelings of abandonment and losing social status. The particularity of the psychotic crises and the process of treatment of schizophrenia as well as persistence and recurrence of the illness trigger the first two components. The grid of social convictions on schizophrenia immensely enhance powerlessness of caregivers. Secrecy seems to be a mean for preventing the anticipated exclusion. In fact it facilitates the sense of helplessness. The collected material suggests that rather than practical social clues, shame and self-stigma determine relatives' coping strategies. A lack of available information and advice for how to support a relative further leads to difficulties, which thus strengthen the feeling of not being able to cope with the situation and undermining the sense of realizing the parental role according to social expectations. The feeling of helplessness is particularly evident with regard to those situations in which relatives receive little support in coping with challenging behaviors of an ill relative or whose relatives refuse treatment.

### Discussion and conclusions

The hereby presented results of the first qualitative study on the phenomenon of stigma experienced by family caregivers of individuals with schizophrenia in Poland base on the data gathered from families and professionals in the urban context. Further research on courtesy stigma should cover the experience of families living in small towns and rural areas, which, due to a limited access to psychiatric care services and non-governmental organizations, might differ from the described context.

The collected material enabled us to describe 'the zone of stigma', i.e., the extent of the changes that social meanings ascribed to this severe mental illness pose on the closest social context of an afflicted individual. The conducted analysis revealed axionormative contradictions in regard to acting as family caregiver to an ill relative and in regard to using potential of patient's family-medical professionals cooperation. The results of our study correspond with what researchers in other countries found out in their contexts in previous years. The main similarities are: caregivers' difficulties with social relations, including contacts with medical professionals and with the closest social environment [6-8, 20]. Other studies from Europe and the USA, similarly to our research, demonstrated the caregivers' tendency to conceal relatives' illness [6, 21] and their feeling of being blamed for their relatives' health problems [2, 8, 10, 20, 22]. Relatives of ill individuals in Germany, alike Polish relatives, talked about

structural discrimination, manifested in a low quality of psychiatric care, burdensome bureaucratic procedures associated with caregiving as well as lack of support [20]. However, the available studies on courtesy stigma, to a lesser extent than our results, described the significance of public discourse on mental illness or access to information about psychiatric treatment [16, 20].

Despite some important changes in the field of psychiatry, including an implementation of a mental healthcare reform, introduction of novel forms of supporting patients and popularization of new models of physician–patients–caregivers relationship, have been taking place in the last decades in Poland, the gathered material suggests that the situation of family caregivers has not received an adequate attention of stakeholders of the psychiatric care system yet. The complexity of the experience of courtesy stigma among family caregivers requires addressing the key components of ‘the zone of stigma’ by social actors managing the healthcare system as well as employees of psychiatric care system, social services and non-governmental organizations. It requires also making efforts to provide families with an immediate and long-lasting informative, instructive and emotional support in accompanying their close ones at various stages of their treatment and recovery as well as in coping with caregivers’ own experiences associated with the relative’s illness. The study results seem to confront also with the urge need to implement educational programs in the field of mental health dedicated to the public, groups professionally related to education, stakeholders and healthcare professionals.

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