


Experience of stigma in the public life of relatives of people diagnosed with schizophrenia in the Republic of Belarus

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Abstract

Purpose Mental health-related stigma affects people with mental disorders and their families. We aimed to investigate the experience of stigma among relatives of patients with schizophrenia in Belarus and formulate recommendations for anti-stigma interventions.

Methods We conducted and thematically analysed 20 interviews with relatives of people diagnosed with schizophrenia. Experience of discrimination, strategies to cope with it, and requests for interventions were examined.

Results A number of themes related to the experience of stigma in the public life of relatives of people with schizophrenia were elicited in relation to: (1) mental health care (difficulties in contacting mental health professionals; in getting appropriate information; lack of alternatives to hospital treatment; absence of appropriate long-term care services); (2) employment of people living with schizophrenia and (3) contact with the police. Analysis of the strategies used to overcome difficulties revealed resignation and passive acceptance, self-reliance, and emotional containment

during crises. Despite the passivity and scepticism in expressing needs, participants suggested a number of interventions that could reduce the burden of stigma.

Conclusions With respect to the public domain of life, substantial stigma and discrimination perceived by families of people living with schizophrenia in Belarus is associated with structural issues of the country's mental health care system. To reduce the stigma-related burden, action must be taken to: (1) educate and support families and (2) deal with structural issues, by reorganising mental health services to better meet the needs of the families of people diagnosed with schizophrenia, and by including them in decision making at all levels.

Keywords Stigma · Schizophrenia · Family studies · Mental health service · Eastern Europe

Introduction

Stigma of mental illness not only affects people living with mental illnesses [1, 2], but also their families [3]. This is referred to as “courtesy stigma” [4], “associative stigma” [5], “stigma by association” [6] or “family stigma” [7] and has been shown to be associated with burden experienced by family members (FMs) [6, 8–10].

However, interventions seeking to reduce family stigma are rare [11]. Moreover, planning and implementation of these interventions is often difficult because there has been little research on mental health-related stigma in low and middle income countries [12, 13]. Since the homogeneity of the stigma concept has been questioned [11, 14, 15], tailoring anti-stigma campaigns to local contexts is necessary in order to address specific challenges and conditions of target populations in specific settings

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and cultures [14, 16]. There is very little evidence about mental health services [17] and the experience of families and others who care for people with schizophrenia in Eastern Europe [12]. To the best of our knowledge, there have never been any studies on stigma experienced by the families of people with a mental disorder in Belarus, although collecting this type of evidence has been identified as an “important mental health priority worldwide” [13].

In this context the aims of this study were: (1) to investigate experiences of stigma-related challenges in the private and public life domains of families of people living with schizophrenia (PLS) in Belarus; (2) to identify *strategies* that FMs use to face the stigma-related challenges in Belarus; (3) to identify relevant and acceptable targets for interventions to help overcome stigma-related challenges for the families of PLS within the Belarusian context. The analysis was focused on the broad range of experiences of stigma rather than the process of stigma per se, i.e. on any examples of devaluation experienced by FMs because of the presence of schizophrenia in the family. To address this research question we hold a realist theoretical position in the analysis to report experience, meaning and reality of participants rather than to unpick the broader social context of these meanings.

In our previous publication, we presented results of the study related to the private domains of life of FMs of PLS, i.e. the experience of stigma and discrimination in the personal relationships, interests, and activities of the respondents [18]. Burdensome experience of family dissolution following a diagnosis in the family was salient in the narratives. The experience of stigma within the secondary social group (such as in relationships with neighbours, friends and colleagues) was characterised by a mismatch between the anticipated stigma and the less obvious perceived discrimination. Strategies to cope with these stigma-related challenges included concealment and “life behind closed doors”, avoidance of the rest of the family, taking full responsibility for the patient and sacrificing one’s personal life by direct caregivers [18].

However, mental-health related stigma is not solely an issue in the private domain of life. It is a persistent predicament with numerous mechanisms and all-pervading negative consequences that go far beyond the private dimension of social interactions and inter-personal communication [19]. Exclusion and discrimination of PLS and their FMs also occur during contacts with medical professionals [20] and in the broader context of medical treatment [21]. Known as “structural discrimination”, this type of stigma appears through intentional and unintentional restrictions by institutional policies, social structures, cultural norms, legal regulations and political decisions [22, 23]. According to some authors, poor quality of mental health services

represents one of the clearest forms of mental health-related structural discrimination [24].

The current paper presents results of the Family Experience of Stigma Study (FESS), related to the experience of stigma and discrimination in the public domain of life of FMs of PLS, i.e. in contacts with social institutions, health care services, the police, the work environment and educational institutions.

Materials and methods

We used a qualitative research methodology and an inductive analytical approach in order to fully take into consideration the perspectives of the study participants [25, 26]. Data were collected between February and September 2014.

The recruitment frame was derived from a case-register of people with a clinical diagnosis of paranoid schizophrenia. According to the country’s regulations, the case-register includes all cases of schizophrenia diagnosed by a certified psychiatrist within governmental mental health care facilities [27]. Therefore, the register contains a broad range of patients both in the early and late stages of the disorder, those living in residential care facilities and independently in communities, and residents of urban and rural areas of the country. The researchers (DK, NK) screened the registers to pre-select cases of potential interest and later contacted the psychiatrist in charge of the selected case to discuss details through the analysis of medical documentation. To obtain data from the capital and a regional city, research participants were recruited in both Minsk and Grodno. We used the following core attributes of the sample to achieved a range on each of the characteristics listed: FM and PLS sex and age (less than 30, 30–50 years, more than 50 years), duration of illness (less than 1, 1–5, 5–10, 10–20 years, more than 20 years), degree of kinship (first degree relative (mother, father, sibling, adult child, partner), second degree relative, distant relative or other). Prior to contacting the identified respondent, we contacted the patient to obtain their written permission to approach the nominated FM. If a positive response was received, a meeting was arranged with the selected FM.

Researchers (DK, NK) explained the study, obtained informed consent and conducted semi-structured in-depth interviews [28] according to a topic guide developed based on a literature review, consultations with service users and mental health professionals (see ESM Appendix A). Interviews lasted approximately 1.5 h, were conducted in Russian, recorded digitally, and transcribed verbatim.

The resulting narratives were then thematically analysed [29]. Given that this was the first exploration of the experiences of families of PLS in Belarus, we chose to use

an inductive approach to coding and analysis rather than a predetermined thematic framework derived from a systematic review of the literature. The authors who undertook the analysis therefore avoided as much as possible having a predetermined analytical framework for the coding and analysis of the data. However, we were unable to use a purely inductive approach (as in Grounded Theory), as it would have involved avoiding preconceptions about the likely experiences of stigma. This methodological approach would have been unrealistic and inappropriate given the professional roles and experiences of the two main researchers (DK, NK) who both are clinical psychiatrists and researchers in stigma. As suggested by Braun and Clarke [29] we made an attempt to code, “without paying attention to the themes that previous research on the topic might have identified”. This allowed us to identify themes from the data and then to compare the findings with other studies, not the opposite.

Two bi-lingual members of the research group (DK, NK) independently coded each interview. The coding was done manually without the use of any computer software. The whole process was accompanied with regular discussions between researchers on discrepancies in coding and structuring materials. After initial familiarization with the data achieved by listening to the recordings, transcribing and re-reading interviews, the analysts highlighted and coded words, phrases and larger sections of text to identify potential patterns. The codes with similar or related meanings were extracted from interviews and collated within candidate themes, which were further reviewed, restructured and named in an iterative process. The thematic map was further refined until there was meaningful coherence within themes, and distinction between them. The final thematic map was discussed with other members of the research team and adjusted until final agreement was reached. The final results and supporting quotations were translated into English and double-checked by bi-lingual (DK, NK) and native English-speaking (SD, JM) authors. The final thematic map of the whole analysis (covering stigma experience in both the private and public domain) was presented in the previous publication [18]. Here we present a detailed list of themes related to stigma experienced in the public domain of life and relevant respondents' citations (ESM Appendix B).

The study was approved by the Ethical Committee of the Belarusian Psychiatric Association (Approval No. 1/e from 27 February 2014).

Results

Participants

The main socio-demographic characteristics of the sample are shown in Table 1. The final sample consisted of 20

Table 1 Socio-demographic characteristics of the sample

Variable	N (%)
Information about respondents	
Gender of respondents	
Male	9 (45)
Female	11 (55)
Age of respondents (Median of age (IQR))	52 (40, 62)
Marital status of respondents	
Single	6 (30)
Married	9 (45)
Divorced	5 (25)
Place of residence of respondents	
Minsk	10 (50)
Grodno	10 (50)
Family relationship to a patient	
Mother	8 (40)
Father	4 (20)
Spouse	2 (10)
Children	2 (10)
Other (siblings, distant relatives)	4 (20)
Family members who are primary caregivers	13 (65)
Family members living together with patients	14 (70)
Information about patients	
Gender of patients	
Male	5 (25)
Female	15 (75)
Age of patients [median of age (IQR)]	35 (28.5, 38.7)
Marital status of patients	
Single	3 (15)
Married	7 (35)
Divorced	10 (50)
Length of patients disorder	
Less than 1 year	1 (5)
1–5 years	2 (10)
5–10 years	5 (25)
10–20 years	9 (45)
More than 20 years	3 (15)
Service utilization at the moment of interview	
In	10 (50)
Out	10 (50)

IQR interquartile range

relatives, composing of 8 mothers, 4 fathers, 2 spouses, 2 children and 4 distant relatives of PLS. The median age of participants was 52 years (IQR 40, 62), 45% of participants were males, and 45% were married at the time of the interviews.

Stigma experience

Experiences of stigma and discrimination in the public domain of life were mentioned by participants in relation to the following three themes: (1) mental health services; (2) employment of PLS; and (3) contact with the police.

Stigma within mental health services

A number of problems experienced within mental health services were reported: (1) difficulties during contacts with mental health professionals; (2) difficulties in getting appropriate information; (3) a lack of alternatives to hospital treatment of PLS and difficulties associated with this for the FMs; (4) absence of appropriate long-term care services.

Examples of difficulties during contacts with mental health professionals included FMs' complaints of abusive and degrading treatment of the PLS in psychiatric hospitals (tying to bed, violence from staff, beating of the patient), and unconfirmed suspicions and fear held by the relatives that the PLS would be punished if they (the relatives) did something wrong.

“When he (son) was hospitalized for the second time, we were allowed to visit him day after day or after two days. He was tied to a bed all the time... and of course it was scary” (Mother, ID1).

Difficulties experienced by FMs during contacts with medical staff within hospitals were mentioned as especially distressing, and examples of inaccessibility, rudeness and ignorance were described. Psychiatrists were described as often overloaded, avoidant, and resistant to contacts with FMs.

“They don't particularly communicate with you... And doctors are all closed in general...” (Husband, ID11).

Negative staff attitudes was presented as interfering with the FM's participation in treatment decision-making and experienced as ignorant and discriminatory towards FMs. On the other hand, respondents also provided examples of positive and caring attitudes from mental health professionals, which they highly appreciated.

“We were just lucky with one doctor. Another would hospitalise and forget, but this woman spoke to her (PLS) carefully, described to us how to treat, what to do. After that we remained out of hospitalisations for a long time” (Mother, ID5).

Difficulties in getting appropriate information about psychiatric treatment and care were presented as a significant issue. This included difficulties in approaching

medical staff and poor contact with them; confusing or inconsistent information being given by different specialists within the mental health services; and an inability to assimilate the information because of emotional shock were mentioned as the main reasons for being insufficiently informed.

“This nurse told me a lot... I asked her what happens with the body... She answered that these patients were all chronic, and that breakdown of the body happened. It killed me” (Mother, ID12).

The lack of information was particularly distressing during the initial stages of the disorder. Families did not know where to get help for PLS and searched among traditional healers, mediums, and specialists in addiction, in addition to seeking help from within churches. Lack of information regarding mental health care sometimes resulted in fear and a perception that psychiatrists were a last resort measure.

Lack of alternatives to hospital treatment (or lack of awareness of their existence) was mentioned as another difficulty associated with the structure of mental health services. This lack of options for managing acute stages (“crises”), and an overreliance on in-patient care indicated ignorance of the needs of FMs and their ill relatives. FMs mentioned this gap in the service provision as forcing to initiate procedures of compulsory hospitalization or postpone the treatment as long as possible, in order to prevent inter-personal conflicts and deterioration of relationships within the family. Hospitalization was perceived as a degrading component of mental health services and associated with a number of hardships, such as long travelling distances, lack of time, space and privacy when visiting due to hospital overcrowding. In some instances, FMs were afraid of asking for additional time with the PLS because of fear that the patient may be punished later by hospital staff. Compulsory hospitalization was perceived as an especially inappropriate solution and associated with feelings of guilt, rage towards PLS, feelings of perplexity and helplessness.

“I don't want to hospitalize her, but what else can I do – it is the only option” (Father, ID10).

Absence of appropriate long-term care facilities in the structure of mental health services was mentioned by FMs as causing substantial difficulties and leading to uncertainty and worry about the future. Although social care houses (“internats”) are offered as an option for PLS in the country, they result in the full deprivation of legal capacity of those admitted; admission to these facilities is associated with shame, resistance, and complicated bureaucratic processes that can take up to five years.

Stigma associated with employment of PLS

Employment difficulties experienced by the PLS was mentioned as a “painful topic” for discussion. Legislative prohibition to work or limitations from holding specific positions led to FMs towards having to find illegal employment for PLS or abandon disability-related benefits in favour of legal employment in a low-paid job. A similar issue was mentioned related to experiences of exclusion from educational establishments due to the PLS’s diagnosis or due to them having lived through a psychotic episode.

The administration called me and said: “We must exclude him, because he is a radio technician—anything may happen here, so ...” He, poor boy, was very upset...For him, it was a very big trauma.” (Mother, ID15).

Stigma associated with contacting the police

Experience of discrimination during contacts with the police was mentioned and described as “painful”, and “rude”, with examples of unreasonable detention and prohibition to take medicines while detained.

“They (policemen) called my mother “dumb” (Son, ID6).

Strategies that FMs use to overcome stigma in the public domain

Strategies to cope with stigma and discrimination in the public domain of life were identified via the thematic analysis of the narratives: (1) resignation and passive acceptance, (2) self-reliance and self-education, and (3) emotional containment during crises.

Resignation and passive acceptance

Respondents seemed unwilling to take actions to improve the situation, defend their rights or express their needs. FMs were not even aware of any possible alternatives and used the concept of “bearing the Cross” (“fate”, “destiny”) to describe their situation, along with experiencing feelings of guilt. Even in situations where there were obvious examples (from the interviewers’ perspective) of discrimination, inhuman and degrading treatment, and violation of rights, respondents tended to rationalize, justify and tolerate the discrimination further and continuously avoid to recognize the situation as a problem requiring actions.

“It is too late—I shall bear this cross till the end. What else? It is my fate to be with an ill person, my destiny” (Mother, ID2).

Self-reliance and self-education

Reliance on mental health care appeared to be relatively low as participants tended to rely on themselves and search for assistance from other (non-medical) sources. Active self-education was used by FMs to compensate for difficulties in contacting medical specialists and hardships associate with mental health services.

“Who else may help me?.. I do everything by myself, and never ask anyone.” (Mother, ID3).

Emotional containment during crises

The lack of alternatives to hospital treatment and conflicts with PLS regarding hospitalization compelled FMs to postpone treatment and cope with the clinical deterioration of symptoms. They tried to contain emotions, and internalize feelings as long as possible and initiated the process of hospitalization only if other strategies proved insufficient and the condition of the patient deteriorated seriously. Among strategies used to deal with crises, respondents described “going away”, “keep staying out of the home”, “work intensively” and leaving the patient alone during the deterioration of the clinical state.

“Sometimes I move to my sister’s and live there for a month or just leave home so not to make the situation worse, not to fight with her” (Son, ID4).

Requests for interventions to decrease the burden of stigma and discrimination in the public life of FMs

Passivity in expression and lack of expectations, together with a predominant reliance on personal resources made it difficult to explore the need for external assistance amongst the relatives of PLS. Participants were skeptical about the possibility of any changes within mental health or other related services and did not believe in the successful implementation of interventions. Sometimes the only request expressed was for the “full recovery” of PLS and whilst understanding that this was unrealistic, respondents were skeptical about anything else.

Nevertheless, participants said that the following strategies would result in decrease of stigma-related burden: (1) changes within mental health care services (development of alternatives to hospitalization and psychopharmacological interventions); (2) development of alternatives to long-term residential care facilities and making independent living

of PLS possible; (3) independent living and employment assistance for PLS.

Changes in mental health services

Participants wished to see the development of alternatives to hospitalization in managing crisis, for example by combining psychopharmacological interventions with rehabilitation and psychological support.

Long-term care facilities and independent living for PLS

Concern for the future of PLS after families were no longer able to provide care prompted requests for services that could support independent living and the future life of a patient. As described above, the residential social care facilities that are currently provided were mentioned as inappropriate and the development of other forms of long-term care would be highly appreciated.

Assistance in the life of PLS

Apprehension that the patient may be deprived of their rights or left in difficult circumstances combined with a fear that people may use the diagnosis to their own advantage, lead to the request by FMs to have better legal defense for PLS. The future—when the family will not be able to play the role of carers—was a matter of particular concern. Employment assistance for PLS was also seen as highly important. However, many were hesitant regarding PLS's ability to work and thus expressed needs of assistance not merely to find an adequate job, but also to conduct a proper assessment of their ability to work and of the help needed in carrying out the job's responsibilities.

Discussion

To the best of our knowledge, the current study is the first attempt to analyse first-hand service user's experience of mental health-related stigma and discrimination in contacts with social institutions in Eastern European country.

Results suggest that one of the main sources of distress reported by families taking part in the study was the difficulties experienced within mental health services. As noted in the introduction, the vast majority of these difficulties fall within the concept of structural discrimination [19, 22], defined as “societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized” [23]. In this broad understanding, structural discrimination has often been reported by the relatives of people with schizophrenia in other studies, in relation to poor quality

of communication with medical personnel, difficulty in accessing information, and lack of support in crisis [4, 9]. Schulze et al.'s focus-group study on patients with schizophrenia, their relatives and mental health professionals, presented the poor quality of mental health services as the strongest form of structural discrimination, which was experienced as a lack of out-patient services, rehabilitation, adequate help in crisis situations and everyday life [24]. In a similar manner, participants in our study emphasised the difficulties in contacts with mental health professionals, poor access to information, lack of alternatives to hospital treatment and psychopharmacological interventions, inappropriateness of current long-term care for PLS, and barriers to employment of PLS.

Despite the broad definition of the structural discrimination provided above, it is not always clear where to draw a line between its obvious examples (such as the formal policies of institutions or legislation which intentionally or unintentionally disadvantage people with mental disorders) and other types of stigma experienced in public services (such as poor contact with psychiatrists, lack of information, “rude” police attitude). In the theoretical framework of stigma in health care settings by Henderson et al. [21], structural stigma was offered as a background factor of mental health services that can shape the knowledge and attitudes of staff working in mental health care and thus their interactions with service users. Using this framework, examples of difficulties experienced by FMs when interacting with mental health professionals and the lack of information provided by them may be an indicator of the weak structure of mental health services and organisations, given that overloaded and burned out professionals with little experience of patients who have successfully recovered may fail to provide attentive care to patients and their families [20]. Unfortunately, mental health-related knowledge and professional contacts alone do not seem to decrease stigmatization among mental health staff [30, 31]. However, practical changes could be made not only by restructuring services, but also by emphasising recovery and increasing social contacts of professionals with patients and their families in everyday lives, rather than only in the context of medical treatment [32, 33].

The prominence of experienced stigma within public services amongst participants of this study can be explained by the nature of mental health care services in Belarus. Despite some progress, the services remain centralised, hospital-based and lacking rehabilitation and community care [34, 35]. It has previously been shown that these types of mental health services are prone to discrimination and human rights abuses [36–38] which has been the impetus for deinstitutionalisation and a shifting locus of care to the community [39] in the USA, Europe, Australia, New Zealand and elsewhere. However, despite multiple calls for a

shift in the locus of care [40] and evidence of cost-effectiveness of redirecting care to the community [41], the shift has not taken place sufficiently in Eastern European countries [17, 42], where mental health care systems are still predominantly hospital based, with recent evidence suggesting that discrimination and even human rights abuses still occur in these institutions [43, 44]. Stigma, resulting in poor political will, is thought to be one of the main barriers for this shift [45].

Discrimination within public services experienced repeatedly throughout an individual's life contribute to the internalization of a "spoiled identity", self-stigma and self-discrimination [46] and as a result—to depression, lower self-esteem, lack of faith in treatment efficacy and an abandonment of efforts to achieve important life goals, together with lower help-seeking behavior [47–50]. It is therefore not surprising that strategies used by families to cope with stigma-related difficulties in the public domain included resignation and passive acceptance, self-reliance, fear and refusal to undertake any actions. Family members predominantly rely on their own resources in providing care for a patient. They are disempowered in taking an active role in the development of mental health services, and are fearful to express their needs. The resulting passivity in expressing needs may then result in a lack of feedback from families regarding the development of mental health care within the country. This process produces a vicious circle of stigma, disempowerment and burden that is difficult to break, and may partially explain the current under-development and near-absence of service users' movements or family organizations in Belarus [51]. Taking this into account, strengthening service user's voices and empowering them should be a priority for future mental health service development in the country [52]. Additionally, there are promising approaches for reduction of self-stigma in schizophrenia, such as the Narrative Enhancement and Cognitive Therapy (NECT) [53], which could be further developed to be implemented with family members of PLS [27].

There is evidence that within countries that have less stigmatizing attitudes, have better access to information, and in which the public is comfortable talking to people with mental illness, the latter have reduced self-stigma and are more empowered [54]. Taken together with evidence that deinstitutionalization has been associated with a decrease of stigma towards those with mental health problems [55, 56], our findings suggest promising directions for future interventions to decrease the burden of family stigma.

Practical implications

Based on the results, we make the following recommendations to reduce the burden of stigma experienced by

families of people with schizophrenia in Belarus. Most of these recommendations involve direct changes to the organisation and delivery of mental health care that are linked to stigmatizing behaviour by public officials and discrimination within services: (1) reconsider the current practice of hospitalization and involuntary admission in favour of the development of community services and support, with alternatives to hospital treatment in managing relapses; (2) provide additional training to improve the communication skills of personnel directly or indirectly involved in the provision of mental health care; (3) improve access to appropriate information, educate and support families in their caring role; (4) provide early intervention for psychosis within a whole family context; (5) reconsider the practice of depriving people with mental disorders of their legal capacity when admitting them into social care housing, in favour of supporting their decision making process, and their ability to live independently in the community; (6) reconsider the practice of employment prohibition in favour of the development of rehabilitation and assistance in the employment of patients; (7) reconsider current criminal law and the practice of detention in favour of better legal defence and treatment for people with mental illness.

Strengths and limitations

Limitations of the study include difficulty in generalising the results because of the qualitative nature of the study and the focus on the views of people who are in touch with mental health services. Purposive sampling was used to obtain maximum variation and therefore to assess all possible forms of stigma phenomena among FM. However, the sample consists of people registered in Minsk and Grodno only and therefore may potentially miss some specific experiences of FMs living in other regions of the country. The background of both researchers involved in data collection and analysis (DK, NK) could also have influenced the findings. To reduce the possibility of bias, all researchers were independent of patients' treatment and interviews were conducted out of the clinical context; we involved mental health professionals and service users while planning and conducting the study. An additional strength is that to the best of our knowledge, this is the first study that attempts to understand the first-hand experience of mental health care in the region by utilizing qualitative research methodology. Given the breadth and depth of the information gathered, the qualitative methods were appropriate for the Belarusian settings to investigate people's experiences, and to provide evidence that families of people with schizophrenia experienced discrimination within the mental health care system, when in contact with the police, and in relation to the employment and education of the patient.

Conclusions

Tackling discrimination within services through staff training and reorganisation of current mental health services in Belarus could help to fundamentally reduce stigma in the public life of family members of people diagnosed with schizophrenia. Reforms and interventions should be designed to better meet the demands of service users and their families, to help them to learn how best to live while caring for a person with mental illness as well as to promote their empowerment and inclusion into the decision- and policy-making processes.

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Compliance with ethical standards

Conflict of interest The authors have no conflict of interest to declare.

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