

Stigma in patients with schizophrenia receiving community mental health care: a review of qualitative studies

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Abstract

Purpose The aim of this review is to identify consistent themes among the qualitative literature on stigma as experienced by patients with schizophrenia receiving community mental health care. With the treatment focus of schizophrenia nowadays shifting more and more towards community-based mental health care, professionals need to be aware of the increased vulnerability of their clients in their social environment as a result of stigma towards their disease. In-depth knowledge on stigma is critical in order to offer a dignifying community mental health care.

Methods A systematic search of the qualitative literature in Web of Science, PubMed, PsycINFO and Francis was performed to review the subjective experiences and ideas on stigma in outpatients with schizophrenia.

Results Three major themes were identified in 18 studies and need to be taken into consideration when implementing an adequate community mental health care: (i) the continuing existence of stigma inherent in the health care setting, (ii) the importance of relational aspects of stigma encounters in daily life and (iii) the significance of the

behavioural aspects related to previous stigma experiences and beliefs among patients.

Conclusions Despite much effort in community treatment, patients still experience stigma and discrimination. Community mental health care professionals should not only be aware of structural problems in mental health care, but should also pay considerable attention towards the relational and behavioural aspects in their clients' life concerning stigma. Furthermore, they have the crucial role in the community to raise awareness about stigma in order to increase their clients' acceptance in society.

Keywords Schizophrenia · Stigma · Discrimination · Community mental health care

Introduction

Schizophrenia is a severe mental disorder with a typical onset in adolescence and young adulthood [1]. The disease shows a global prevalence of 0.3–0.7 % [2] and is believed to make up around 1 % of the total disability adjusted life years (DALYs) worldwide [1]. A distinction can be made between two categories of symptoms viz. negative and positive symptoms. The positive symptoms of schizophrenia manifest themselves inter alia as psychosis with hallucinations, delusions and incomprehensible speech. The main negative symptoms are social withdrawal, self-neglect and loss of motivation and initiative [1].

In addition to these severe symptoms of illness, schizophrenia patients suffer from what is called a “second illness”, which is the social label attached to the disorder [3]. Schizophrenia appears to be amongst the most stigmatising disorders of all mental disorders. Corrigan et al.

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[4] describe three main factors involved in the development of stigma in general, which form a chain of events. First, stereotypes and negative beliefs about a group such as strangeness, dangerousness and incompetence are present in society. This gives rise to prejudice, whenever there is an agreement with the belief and/or a negative emotional reaction towards it. As a consequence, this leads to behavioural responses such as avoidance and withholding help.

Under the World Health Organisation (WHO) influence, the treatment focus in Europe for serious mental disorders like schizophrenia is currently shifting more and more from residential hospital-based programmes towards ambulatory community-based mental health care such as early detection and intervention programmes for psychosis (EDIP) [5–7]. It is believed that this shift could lead to a broader access to mental health care, which would subsequently lead to a more successful therapy and diminish the percentage of care-averse patients. Besides the beneficial effects on disease progression, the encouragement for active participation and empowerment could be stigma-diminishing since patients are no longer ‘tucked away’ in the hospital and are able to take up their normal societal roles in their families and employment situation. However, patients are also more vulnerable to stigmatising reactions or opinions from the media or public opinion, since they are no longer in the protected environment of the hospital. It is therefore unclear whether community-based mental health care programmes are stigma-diminishing or exactly the opposite. In order to ensure an adequate and dignifying community mental health service according to the WHO declarations, stigma and discrimination reduction is critical and should endure to be a major focus in the gradual improvement of these services [6, 8].

Review

Aim

The purpose of this research paper is to review the qualitative literature concerning the subjective experiences and ideas on stigma in patients with schizophrenia who are receiving outpatient community mental health care. Identification of consistent themes across these studies can provide a well-founded base for stigma-diminishing measures. This paper will, for the first time, provide a comprehensive overview of qualitative research with patients already in the community mental health care. Providing this overview is a first step in developing and implementing a mental health care able to meet the standards of a respectful care.

Methodology

Since techniques for including and synthesising qualitative evidence remain under-developed compared to the synthesis of quantitative evidence [9], the newly described Qualitative Analysis Guide of Leuven (QUAGOL) was applied as a guide for this literature review to capture the insights of the qualitative data in the included studies [10]. Although the primary interviews were not accessible, the result section of the included studies was used as the source for analysis. QUAGOL enables the researcher to work systematically and is inspired by the constant comparative method of the Grounded Theory approach. The process consists of two steps: the preparation of the coding data and the coding process. The former allows the researcher to deliberately postpone the actual coding process and happens by paper and pencil work. A first glimpse of the concepts and further insights are gathered in this first stage, and a list of contextual and meaningful concepts is drawn up. Only in the second stage, coding software is used to allow a systematic analysis of the concepts based on the data, ending with an empirically based description of the results [10]. For the purposes of this systematic review, the licence-based qualitative analysis software NVivo 9.2 was applied. Quotes are included within the results section to clarify the discussed themes and to give credit to the individual studies and its participants.

Search strategy

A systematic search of the literature was performed using the following databases: Web of Science, PubMed, PsycINFO and Francis. The search strategy combined the following key words and related words to look for articles with the envisaged content and methodology: stigma, discrimination, patients, psychosis, schizophrenia, mental illness, qualitative, focus, semi-structured, interview and empirical. Articles were included if they met each of the following criteria: (1) primary, empirical research with qualitative or mixed-method design, (2) concerned patients with a schizophrenia-related disorder or primary psychosis, (3) concerned patients receiving community mental health care, (4) concerned the stigma experiences and/or beliefs of these patients (5) performed in USA, Canada, UK, Europe or Australia and (6) published in English. Views of relatives or mental health care professionals on stigma were not taken into account for the analysis. Content and validity of the articles was evaluated using a modified quality checklist for qualitative research in order to exclude low-quality studies [11].

Search outcome

The literature search yielded 18 articles. The majority of the studies were conducted in the UK ($n = 7$), closely

followed by the USA ($n = 5$) and Europe ($n = 4$). One study was performed in Australia and another study reported results from research conducted at 15 different sites in Europe, the USA and other countries, including Turkey, Brazil and Malaysia. Seven articles specifically examined stigma in patients with schizophrenia [12–18], while the other articles focused on other topics but where the experience of stigma was revealed along with the narratives [19–29]. Most research settings consisted of community-based mental health care services or outpatient psychiatric services ($n = 14$; [12, 13, 16, 17, 19, 20, 22–29]). Three studies had a mixed setting with outpatients as well as hospitalised or group therapy patients [14, 15, 21]. Rose et al. [18] stated that most participants in their multinational study were receiving outpatient care.

Methodological features of the articles

The sample size of the selected studies was diverse; five articles showed sample sizes between 5 and 8 participants [13, 21, 23, 24, 28]; in seven studies, 15–30 patients participated [12, 14, 15, 19, 25, 26, 29], and in four other studies, the sample size varied between 75 and 90 subjects [16–18, 20]. Lester et al. [22] performed the largest study with 202 participants. It must be noted that the three studies of Jenkins and Carpenter-Song [16, 17, 20] used the same study participants. Most participants were included in the study if they had an International Statistical Classification of Diseases and Related Health Problems (ICD-10) or Diagnostic and Statistical Manual of Mental Disorders [DSM-IV; Structured Clinical Interview for DSM Disorders (SCID)] diagnosis of schizophrenia, or if they had previously been given a clinical diagnosis of schizophrenia. Sampling in the study of Chernomas et al. [19] was based on a self-identified diagnosis of schizophrenia or schizoaffective disorder. The studies mainly made the distinction between schizophrenia and schizoaffective disorder, but schizophreniform disorder and psychotic disorders (first episode or not otherwise specified) are also mentioned.

Critical appraisal

As mentioned supra, content and validity of the articles was evaluated using a modified quality checklist for qualitative research to exclude low-quality studies whenever less than five out of nine criteria were met [11]. The selected criteria included justification of the qualitative research design, explanation on participant recruitment, audio taped and verbatim transcription of data, representation of original quotes in the article, a clear description of the contribution of the research, analysis by multiple assessors, respondent validation, mentioning of data saturation, and ethical review [informed consent (IC) and

approval by ethics committee(EC)]. Table 1 below represents the different articles and criteria.

All studies met the five criteria of justification of the qualitative research design, explanation on recruitment strategy, audio taped and verbatim transcription of data, representation of original quotes in the article and a clear description of the contribution of the research, thereby proving to be of a considerable standard for assessment in this review. Next to these criteria, all authors mentioned analysis of data with multiple assessors, except for McCann [29]. For ethical review, the evaluation is more complex. Approximately half of the authors mentioned approval by an EC accompanied by an IC procedure [13, 22, 24–29]. Other studies only stated an IC procedure without mentioning EC approval [12, 14–17, 19–21]. Against all expectations, two studies did not mention any ethical review, which is uncommon for research with patients [18, 23]. Notwithstanding the overall fair quality of the included studies, few answered to the criteria of saturation and respondent validation. Only Barker et al. [21] and Lester et al. [22] mentioned respondent validation, while saturation was only considered in the latter [22]. However, it must be taken into consideration that some of these criteria could have been fulfilled without being mentioned in the articles.

Results

Three major themes concerning stigma were identified across the selected literature. First, the experiences of patients with schizophrenia in their contact with mental and regular health care will be discussed. Secondly, an overview of the relational aspect of stigma in everyday life of these patients will be provided. Thereafter, the third part describes the behavioural aspect related to stigma experiences of the patients. The last paragraph gives an impression of the positive encounters from patients. These encounters could provide some valuable insight in how people with schizophrenia want to be treated in a community-based mental health care system and could give suggestions towards possible stigma-diminishing measures.

Stigma in the health care system

The majority of the studies discussed in this review show that patients report to experience a lot of discriminatory or stigmatising behaviour in the context of psychiatric as well as somatic health care [12–15, 19–23, 25, 27]. Patients feel they are not taken seriously and feel discriminated in the sense that they are denied access to a normal doctor–patient relationship. Patients feel that they are treated in a paternalistic way without respect, and that they are not receiving

Table 1 Quality assessment for included studies

Selected articles	Other criteria ^a	Analysis by multiple assessors	Respondent validation	Data saturation	Ethical review
Chernomas et al. (2000) [19]	✓	✓	–	–	IC
Barker et al. (2001) [21]	✓	✓	✓	–	IC
Lester et al. (2003) [22]	✓	✓	✓	✓	EC
Schulze and Angermeyer (2003) [12]	✓	✓	–	–	IC
Lloyd et al. (2005) [13]	✓	✓	–	–	IC + EC
Jenkins and Carpenter-Song (2005) [20]	✓	✓	–	–	IC
Perry et al. (2007) [23]	✓	✓	–	–	–
Gonzalez-Torres et al. (2007) [15]	✓	✓	–	–	IC
Buizza et al. (2007) [14]	✓	✓	–	–	IC
Nithsdale et al. (2008) [24]	✓	✓	–	–	IC + EC
Forrester-Jones and Barnes (2008) [26]	✓	✓	–	–	IC + EC
Judge et al. (2008) [25]	✓	–	–	–	IC + EC
Jenkins and Carpenter-Song (2008) [16]	✓	✓	–	–	IC
Jenkins and Carpenter-Song (2009) [17]	✓	✓	–	–	IC
McCann (2010) [29]	✓	–	–	–	IC + EC
Redmond et al. (2010) [28]	✓	✓	–	–	IC + EC
Tidefors and Olin (2010) [27]	✓	✓	–	–	IC + EC
Rose et al. (2011) [18]	✓	✓	–	–	–

IC informed consent, EC ethics committee approval

^a Justification of the qualitative research design, explanation of recruitment strategy, audio taped and verbatim transcription of data, representation of original quotes in the article and clear description of the contribution of the research

the appropriate information concerning their disease and treatment possibilities. In many cases they are not allowed to take part in the decision-making process, and questioning a certain treatment is even looked upon as being an uncooperative patient.

“Then it’s a bit in line with my experience, this view in psychiatry that if you complain and want to change doctors and you have a lot of opinions about your treatment, you can be called an “uncooperative patient.” And then you can get that stamp/.../the attitude of one of the doctors who was very authoritarian and definite and very concentrated on medication—that was sort of it, nothing else. So I felt rather bullied” [27].

Interestingly, two studies reported the same lack of respect or involvement for non-psychiatric somatic problems [12, 15]. Patients reported having to wait longer than

other patients, being ridiculed, or facing suspicion that their physical complaints may only be imaginary.

“Until they discovered what I have (kidney stones), they didn’t listen to me, it was all due to nerves, whenever I said my stomach ached, this side ached, it was nerves...” [15].

In addition to these problems, patients reported experiencing structural discrimination [12, 14, 22, 25, 27]. The existing mental health care facilities are felt to be insufficient, and people experience an impersonal approach which focuses on efficiency instead of the patient. There is a discontinuity of care and, consequently, patients have to retell their story to every other psychiatrist. For them, an adequate psychiatric treatment exists in a comprehensive plan for treatment and rehabilitation which takes into account the patients’ narrative and the difficulties they face outside the hospital. The necessity of the continuity of care

is stressed, where in-patient treatment, after-care and reintegration services, as well as community-based treatment, interact with each other and help the patients to get involved in their own life.

Relational aspects of stigma encounters in everyday life

Prejudice of violence and unpredictability

The prejudice of violence and unpredictability is commonly found in the literature; the media portrayals of mental illness and schizophrenia in particular frequently take place in the context of court and police reporting. In nearly half of the studies, the participants mention public bias in information as one of the main causes of stigma and discrimination [12, 14, 15, 17–19, 26]. On top of this there is the stigmatisation caused by a wrong image; participants in the study of Schulze et al. [12] perceive the dominance of negative images as an integral part of the hurtful stigmatisation experience.

“I think there’s a tendency, everyone assumes, you know, the mentally ill that I’m a danger to society. I’m more a danger to myself than anyone else” [17].

“The media... as soon as something happens... someone gets killed... it was a mentally disturbed person who had schizophrenia” [15].

Reduction of social contacts

Patients with schizophrenia encounter many difficulties on an interpersonal level, such as the reduction of social contacts they experience as a result of the schizophrenia diagnosis [12–15, 17–19, 28]. In the first place this loss of social interactions is noticed in the closer social circle like relatives, partners and friends.

“Yes. All my friends turned away of me. They start to avoid contacts with me. They just stopped to communicate with me, broke the relations. My illness was strong disadvantage for me” [18].

Besides this, many articles also underscore the social isolation when dealing with more anonymous or ‘further’ social contacts like working colleagues, neighbours and the people on the street. Patients report not being understood and being mocked. In this context, the studies indicate that the superficiality and carelessness with which psychiatric terms are used in everyday language can also play a role [14].

“At the beginning of my illness, when my neighbours found out about it, they said: ‘This lunatic has to be left alone’ [18].

Patients want to be taken seriously

Another subtheme that emerged in almost all of the studies in the domain of interpersonal relationships was that patients want to be treated like anybody else and want to be taken seriously [12–15, 17–23, 26, 27, 29]. They do not want to be treated as “mentally ill” or incapable of making their own decisions. However, many patients experience paternalism and overprotection in the encounter with family members, partners, GP and mental health care staff.

“Well, my closest relatives like to decide for me, all the time. Sometimes it’s almost like I was declared incapable of managing my own affairs” [18].

Furthermore, patients feel denied in their caring relationship needs and experience a lack of privacy due to the overprotection of caregivers [28, 29]. Insinuations or clear statements are made that they should not be involved in romantic entanglements or parental duties [20]. Patients experience a complete opposition when mentioning the possibility of having children [15, 18, 20, 29].

Unsupportive working situation

Almost half of the articles describe discrimination related to work and hiring possibilities [12, 14, 15, 17, 19, 21, 24]. Many patients felt that their workplaces had been unsupportive and that there was a low tolerance and understanding for their illness. Employees were given menial work, their duties were restricted and they were refused time off to see mental health professionals. Often, insinuations were made that patients should leave their jobs. These circumstances are worsened by rejection and discrimination by working colleagues, and make the participants feel insecure about losing their job and the possibility to return to their job after a period of psychiatric treatment.

Behavioural aspects related to stigma experiences

It is important to take a closer look at the patients’ behaviour, since many of the previously discussed topics are undeniably intertwined with it and all mental health care professionals will need to handle it with due care.

In the majority of the investigated studies, patients indicate that they fear exclusion and discrimination linked with their diagnosis [12, 14, 16, 17, 19, 23–26, 28, 29]. Consequently, most of them hide their diagnosis and conceal symptoms and medication use, or disclose their diagnosis to close relatives only.

“I don’t tell. I just find that telling a person... they don’t understand... especially with schizophrenia,

they think they're going to be murdered by you, so I don't like to mention anything" [19].

Aside from secrecy strategy, patients feel discouraged to maintain their social contacts and, as such, reinforce their own social isolation. Although social withdrawal is sometimes seen as a negative symptom of schizophrenia, the experiences described above could be among the driving forces for patients to hide their diagnosis and to avoid contact. These self-protection strategies of patients are described more in detail by Jenkins and Carpenter-Song [16]. Other stigma-resisting strategies include educating others about mental illness and socialising with others with mental illness; the latter strategies are described in the results of other studies as well [24].

McCann's [29] results confirm the findings of Jenkins and Carpenter-Song [16], showing that patients are more likely to meet other people with a mental illness. This 'skewing' towards primarily meeting people involved in mental health care is, on the one hand, seen as a hindrance for building up a variety of social contacts, but is, on the other hand, sometimes caused by the preference of the patients themselves towards comfortable and recognisable contacts with people whom they believe are in the same situation and who are, therefore, expected to be more supportive towards the problems they encounter [18, 23].

"People who are ill themselves and know that I am ill do not avoid me. But those who are not ill but know that I am ill do avoid me" [18].

The other side of the coin?

It has to be noticed that next to the discriminating behaviour in society towards them as a consequence of schizophrenia, many articles underscore that participants also experienced positive encounters in daily social contacts and treatment in the professional mental health care system. Half of the studies highlight the importance of having other supportive people around [17, 19–24, 26, 27]. Support from family, friends and health care professionals is highly appreciated by patients as a help to build up confidence and to better cope with their disease. Patients value the personal attention and gather strength to undertake further steps in their lives such as getting back to work and meeting other people.

Strangely enough, the same support is mentioned in the study of Rose et al. [18] when patients are asked whether they sometimes experience 'positive discrimination' as a consequence of their disease. Thus, they attribute these

positive experiences to their diagnosis and look upon it as a beneficial side effect of their illness:

"I have been out with nice people as well who helped me without asking for something in return from me" [18].

Discussion

Methodological issues

The use of QUAGOL as a methodological approach for a systematic review with a secondary analysis of research data is rather innovative and can be recommended to other authors since it enables a systematic framework for this analysis. The advantage of this methodology is its combination of intuitive 'peopleware' in the initial stage of the analysis where an initial glimpse of the concepts and basic insights are gathered, followed by a software-based analytical end stage. Other strengths are the constant forward–backward movement using the comparative method and the combination of within-‘case’ and cross-‘case’ analysis [10]. One of the problems that one faces when analysing numerous qualitative research articles for systematic review is the use of different methodologies in each paper. However, since QUAGOL is not a rigid methodology and combines different analytical approaches, the integrity of each individual paper can be retained and leads to the identification of important overlapping themes in the subject matter.

The major limitation of this systematic review is that its results are strongly dependent on the availability and interpretation of data in the individual research papers. However, it is expected that the most relevant and important themes are captured with this methodology and that the methodology enables one to provide a broad overview of the qualitative literature available on a certain topic.

Since there are few previous examples of qualitative analysis techniques applied to systematic reviews, this methodology can be a valuable backbone tool in the reviewing process. Reliable and professional methods are crucial for reviewing studies, especially in the context of qualitative approaches which tend to be more subject to personal interpretation.

Substantial findings

The goal of this review was to identify recurrent themes in the qualitative literature about stigma in patients with schizophrenia receiving outpatient care. These insights are necessary for an increased understanding of the existing

mental health care setting and form part of the first critical stage in the entire process of fine-tuning and adapting the existing health care services, in order to ensure a dignifying mental health care, where people are not stigmatised on the basis of their condition in their contacts with health care professionals or their social environment.

Notwithstanding the great variety of countries included in the different studies, considerable consistency in the assessed studies among the patients' experiences was found. Accordingly, these findings and implications give a broader overview than could be achieved by any single one of the small sample size qualitative studies. Although complete generalisability can probably never be reached, these results strengthen the research findings of each of these groups and suggest that a commonly shared experience of stigma attached to schizophrenia exists. Hence, implications and suggestions drawn from this overview can be expected to be relevant for mental health care professionals working in a wider mental health care setting.

When discussing community mental health care programmes, many authors in the field of psychiatry and bioethics point toward the risk of stigmatisation as a potential side effect of inclusion of patients with schizophrenia in society when organising community mental health care, such as EDIP services [30–32]. This review proves that stigmatisation of community patients is not quite an unfounded concern as will be further discussed in the following two paragraphs.

Stigma in health care

Surprisingly, the results discussed above show that stigmatising behaviour not only occurs when coming into contact with people with limited knowledge or familiarity with schizophrenia, but is a common experience in contacts with health care professionals as well, and was previously described by Thornicroft et al. [33]. Notwithstanding their knowledge on mental illness, which can be assumed to be part of any medical training, health care personnel are reported by patients as also falling prey to common stereotypes and prejudices. According to patients they are not taken seriously and are not respected in comparison with the conventional doctor–patient relationship. This is peculiar in our era where decisional autonomy is believed to be one of the basic principles of an ethical health care system [34]. Although it is sometimes rather challenging to assess the competency of mentally ill patients, since their beliefs and understandings may be affected by the positive symptoms such as delusions and hallucinations or lack of insight in their disease [35], the presence of schizophrenia does not necessarily mean that the patient has an impairment in capacity and that the principle of respect for autonomy can be ignored [36]. Importantly, respect for

autonomy does not necessarily imply uncritical acceptance of others' choices, but it does include "...building up or maintaining others' capacities for autonomous choice while helping to allay fears and other conditions that destroy or disrupt autonomous action" [34]. In this sense, it becomes clear that health care professionals have the moral obligation to involve their patients, whether they have a mental condition or not, in the decision-making process, or that they at least should try to empower them to be part of these decisions. At first glance, this could seem quite unfeasible, but the positive experiences from the participants in the different studies prove it not to be insurmountable. All participants highly value the support of health care professionals or social workers in the different aspects of their life, especially when offered in a non-paternalistic fashion. Providing space for customised information-giving and subsequent decisional autonomy remains one of the main approaches to stimulate patient involvement and therapy adherence. Woltmann and Whitley [37] emphasise the partnership aspect of decision-making as being crucial, since mental health care consumers seem to be more interested in a trusting health care partnership with deliberation than in the actual content of the decision. Such a health care partnership would be particularly relevant in the long-term context of mental health care, where patient empowerment could prove to be more efficient and valuable than a paternalistic vision in which patients have the tendency to discontinue treatment. Quirk et al. [38] show that patient empowerment is not an empty concept and that in fact a lot of health care professionals are already implementing this in their regular practice for example when drug adherence is discussed between the patient and psychiatrist. Hence, finding the right balance between empowering and support will be crucial for professionals [31].

In a health care setting, the first step towards more awareness and reduced prejudices by health care professionals could be to bring them into contact with mental health care consumers already during their medical training, since some studies reported a positive influence of direct and indirect contact between these two groups [39, 40].

Relational and behavioural aspects of stigma

The importance of the interaction between people with schizophrenia and the people surrounding them such as relatives, neighbours and colleagues should not be underestimated. The complex interplay between the patient, his surrounding environment and proposed treatment plan, has to be taken into consideration by mental health care professionals, since all these factors can affect the patient and his condition.

Stigma and discrimination can lead to social exclusion, limited employment and reduced housing opportunities, which, in turn, can influence the psychiatric condition [41, 42]. Furthermore, these reduced social opportunities are believed to be factors conducive to severe mental illness which can cause an elevated level of violence [43]. In this way, the generalised prejudice about violence and unpredictability in schizophrenia patients, and the discrimination resulting from this, become a self-fulfilling prophecy, and the patients are plunged into a downward spiral. However, the relational aspect is two-sided and becomes more complex when anticipated stigma is also taken into account. Patients base their expectations concerning social contacts on previous experiences as well as on their own prejudices about how society deals with mental health consumers, which leads to anticipation of stigma [3, 44, 45]. Although this is reasonable sociological behaviour, a clash between anticipations arises. Friends, relatives and acquaintances anticipate elevated violent behaviour, together with other commonly heard prejudices, while patients anticipate the stigma resulting from these prejudices. This stands in the way of an open encounter where both sides are valued because of who they are.

Conclusion

Despite the extensive amount of effort undertaken in a lot of countries for raising awareness in mental health, this research, reviewing recent studies from the last decade, shows that patients still experience stigmatising behaviour even though they are already in the community mental health care setting which was developed as a quest for a socially acceptable, empowering and stigma-diminishing mental health care. These results support the view that much more needs to be done to reach the standards of a dignifying mental health care where the principles of a respectful care are taken into consideration. This review serves to illustrate the assumption that the inclusion of patients with schizophrenia in society is not without risk when considering stigma, and that a community mental health care ought to offer far more than medical treatment. Health care professionals in community mental health care should display considerable attention towards all three stigma themes, as described supra, because they are highly intertwined with each other. Disregarding one of the themes, could have a major impact on the other two. A stigmatising encounter with a health care professional could, for instance, lead to a diminished self-esteem and cause the patient to distrust the health care system and other supporting individuals, thereby promoting his social isolation and influencing his relational environment as well as his working situation. Hence, health care professionals

should be very aware of their own possible stigmatising attitudes and should also focus on the relational environment of their patients and how this influences their behaviour. This can be reached by empowering their clients to strengthen their ability of living and functioning in the community by supporting them in, for example, their job search or setting up buddy projects where clients can meet other people from the community. Furthermore, the role of a community mental health care should be to raise awareness about stigma in its own health care network as well as in the community. Involvement of both service users and community members could be crucial in order to make such an effort accurate and efficient.

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Conflict of interest None.

References

- Picchioni MM, Murray RM (2007) Schizophrenia. *BMJ* 335(7610):91–95. doi:10.1136/bmj.39227.616447.BE (England)
- van Os J, Kapur S (2009) Schizophrenia. *Lancet* 374(9690):635–645. doi:10.1016/s0140-6736(09)60995-8 (England)
- Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M (2009) Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet* 373(9661):408–415. doi:10.1016/S0140-6736(08)61817-6
- Corrigan PW (2000) Mental health stigma as social attribution: implications for research methods and attitude change. *Clin Psychol Sci Pract* 7(1):48–67. doi:10.1093/clipsy/7.1.48
- World Health Organisation (2005) Mental health declaration for Europe. WHO regional office for Europe, Copenhagen
- Semrau M, Barley EA, Law A, Thornicroft G (2011) Lessons learned in developing community mental health care in Europe. *World Psychiatry* 10(3):217–225
- World Health Organisation (2005) Mental health action plan for Europe. WHO regional office for Europe, Copenhagen
- World Health Organisation (2005) Mental health: facing the challenges, building solutions. Report from the WHO ministerial conference. WHO regional office for Europe, Copenhagen
- Dixon-Woods M, Fitzpatrick R, Roberts K (2001) Including qualitative research in systematic reviews: opportunities and problems. *J Eval Clin Pract* 7(2):125–133 (pii jep257)
- Dierckx de Casterlé B, Gastmans C, Bryon E, Denier Y (2011) QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud*. doi:10.1016/j.ijnurstu.2011.09.012
- Critical Appraisal Skills Program (CASP) (2003) 10 questions to help you make sense of qualitative research, Oxford. <http://www.sph.nhs.uk/sph-files/casp-appraisaltools/Qualitative%20Appraisal%20Tool.pdf>. Accessed 28 Feb 2012
- Schulze B, Angermeyer MC (2003) Subjective experiences of stigma. A focus group study of schizophrenic patients, their

- relatives and mental health professionals. *Soc Sci Med* (1982) 56(2):299–312
13. Lloyd C, Sullivan D, Williams PL (2005) Perceptions of social stigma and its effect on interpersonal relationships of young males who experience a psychotic disorder. *Aust Occup Ther J* 52(3):243–250. doi:10.1111/j.1440-1630.2005.00504.x
 14. Buizza C, Schulze B, Bertocchi E, Rossi G, Ghilardi A, Pioli R (2007) The stigma of schizophrenia from patients' and relatives' view: a pilot study in an Italian rehabilitation residential care unit. *Clin Pract Epidemiol Ment Health* 3:23. doi:10.1186/1745-0179-3-23
 15. Gonzalez-Torres MA, Oraa R, Aristegui M, Fernandez-Rivas A, Guimon J (2007) Stigma and discrimination towards people with schizophrenia and their family members—a qualitative study with focus groups. *Soc Psychiatry Psychiatr Epidemiol* 42(1):14–23. doi:10.1007/s00127-006-0126-3
 16. Jenkins JH, Carpenter-Song EA (2008) Stigma despite recovery: strategies for living in the aftermath of psychosis. *Med Anthropol Q* 22(4):381–409
 17. Jenkins JH, Carpenter-Song EA (2009) Awareness of stigma among persons with schizophrenia marking the contexts of lived experience. *J Nerv Ment Dis* 197(7):520–529. doi:10.1097/NMD.0b013e3181aad5e9
 18. Rose D, Willis R, Brohan E, Sartorius N, Villares C, Wahlbeck K, Thornicroft G (2011) Reported stigma and discrimination by people with a diagnosis of schizophrenia. *Epidemiol Psychiatr Sci* 20(2):193–204. doi:10.1017/S2045796011000254
 19. Chernomas WM, Clarke DE, Chisholm FA (2000) Perspectives of women living with schizophrenia. *Psychiatr Serv* 51(12):1517–1521. doi:10.1176/appi.ps.51.12.1517
 20. Jenkins JH, Carpenter-Song E (2005) The new paradigm of recovery from schizophrenia: cultural conundrums of improvement without cure. *Cult Med Psychiatry* 29(4):379–413. doi:10.1007/s11013-006-9000-8
 21. Barker S, Lavender T, Morant N (2001) Client and family narratives on schizophrenia. *J Ment Health* 10(2):199–212. doi:10.1080/09638230123705
 22. Lester H, Tritter JQ, England E (2003) Satisfaction with primary care: the perspectives of people with schizophrenia. *Fam Pract* 20(5):1–11. doi:10.1093/fampra/cm9502
 23. Perry BM, Taylor D, Shaw SK (2007) You've got to have a positive state of mind: an interpretative phenomenological analysis of hope and first episode psychosis. *J Ment Health* 16(6):781–793. doi:10.1080/09638230701496360
 24. Nithsdale V, Davies J, Croucher P (2008) Psychosis and the experience of employment. *J Occup Rehabil* 18(2):175–182. doi:10.1007/s10926-008-9131-6
 25. Judge AM, Estroff SE, Perkins DO, Penn DL (2008) Recognizing and responding to early psychosis: a qualitative analysis of individual narratives. *Psychiatr Serv* 59(1):96–99. doi:10.1176/appi.ps.59.1.96
 26. Forrester-Jones R, Barnes A (2008) On being a girlfriend not a patient: the quest for an acceptable identity amongst people diagnosed with a severe mental illness. *J Ment Health* 17(2):153–172. doi:10.1080/09638230701498341
 27. Tidefors I, Olin E (2011) A need for “good eyes”: experiences told by patients diagnosed with psychosis. *Int J Qual Stud Health Well Being* 6(1) doi:10.3402/qhw.v6i1.5243
 28. Redmond C, Larkin M, Harrop C (2010) The personal meaning of romantic relationships for young people with psychosis. *Clin Child Psychol Psychiatry* 15(2):151–170. doi:10.1177/1359104509341447
 29. McCann E (2010) Investigating mental health service user views regarding sexual and relationship issues. *J Psychiatr Ment Health Nurs* 17(3):251–259. doi:10.1111/j.1365-2850.2009.01509.x
 30. Harrison J, Gill A (2010) The experience and consequences of people with mental health problems, the impact of stigma upon people with schizophrenia: a way forward. *J Psychiatr Ment Health Nurs* 17(3):242–250. doi:10.1111/j.1365-2850.2009.01506.x
 31. Liegeois A, Van Audenhove C (2005) Ethical dilemmas in community mental health care. *J Med Ethics* 31(8):452–456. doi:10.1136/jme.2003.006999
 32. Corcoran C, Malaspina D, Hercher L (2005) Prodromal interventions for schizophrenia vulnerability: the risks of being “at risk”. *Schizophr Res* 73(2–3):173–184. doi:10.1016/j.schres.2004.05.021 (The Netherlands)
 33. Thornicroft G, Rose D, Kassar A (2007) Discrimination in health care against people with mental illness. *Int Rev Psychiatry* 19(2):113–122. doi:10.1080/09540260701278937
 34. Beauchamp TL, Childress JF (2009) Principles of biomedical ethics, 6th edn. Oxford University Press, New York
 35. Grisso T, Appelbaum PS (1995) The MacArthur treatment competence study III: abilities of patients to consent to psychiatric and medical treatments. *Law Hum Behav* 19(2):149–174
 36. Jeste DV, Depp CA, Palmer BW (2006) Magnitude of impairment in decisional capacity in people with schizophrenia compared to normal subjects: an overview. *Schizophr Bull* 32(1):121–128. doi:10.1093/schbul/sbj001
 37. Woltmann EM, Whitley R (2010) Shared decision making in public mental health care: perspectives from consumers living with severe mental illness. *Psychiatr Rehabil J* 34(1):29–36. doi:10.2975/34.1.2010.29.36
 38. Quirk A, Chaplin R, Hamilton S, Lelliott P, Seale C (2013) Communication about adherence to long-term antipsychotic prescribing: an observational study of psychiatric practice. *Soc Psychiatry Psychiatr Epidemiol* 48(4):639–647. doi:10.1007/s00127-012-0581-y
 39. Nguyen E, Chen TF, O'Reilly CL (2012) Evaluating the impact of direct and indirect contact on the mental health stigma of pharmacy students. *Soc Psychiatry Psychiatr Epidemiol* 47(7):1087–1098. doi:10.1007/s00127-011-0413-5
 40. O'Reilly CL, Bell JS, Chen TF (2012) Mental health consumers and caregivers as instructors for health professional students: a qualitative study. *Soc Psychiatry Psychiatr Epidemiol* 47(4):607–613. doi:10.1007/s00127-011-0364-x
 41. Markowitz FE (2011) Mental illness, crime, and violence: risk, context, and social control. *Aggress Viol Behav* 16(1):36–44. doi:10.1016/j.avb.2010.10.003
 42. van Zelst C (2009) Stigmatization as an environmental risk in schizophrenia: a user perspective. *Schizophr Bull* 35(2):293–296. doi:10.1093/schbul/sbn184 (United States)
 43. Elbogen EB, Johnson SC (2009) The intricate link between violence and mental disorder. *Arch Gen Psychiatry* 66(2):152–161
 44. Ucock A, Brohan E, Rose D, Sartorius N, Leese M, Yoon CK, Plooy A, Ertekin BA, Milev R, Thornicroft G, Indigo Study Group (2012) Anticipated discrimination among people with schizophrenia. *Acta Psychiatr Scand* 125(1):77–83. doi:10.1111/j.1600-0447.2011.01772.x
 45. Moriarty A, Jolley S, Callanan MM, Garety P (2012) Understanding reduced activity in psychosis: the roles of stigma and illness appraisals. *Soc Psychiatry Psychiatr Epidemiol* 47(10):1685–1693. doi:10.1007/s00127-012-0475-z