DEVELOPING TRUST AND EFFECTIVE CARE FOR PEOPLE WITH SCHIZOPHRENIA: PATIENTS AND PSYCHIATRISTS WORKING IN PARTNERSHIP

A JOINT PROJECT BETWEEN GAMIAN-EUROPE
AND THE EUROPEAN PSYCHIATRIC ASSOCIATION

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CONTENT

EXECUTIVE SUMMARY

This report presents the findings and recommendations of a joint partnership project between GAMIAN-Europe and the European Psychiatric Association (EPA) to strengthen and improve the therapeutic relationship between patients with schizophrenia and their psychiatrists.

The project aimed to understand from the perspective of patients and psychiatrists:

- The positive and negative experiences of their therapeutic relationship;
- The interaction between patients and their psychiatrist;
- What facilitates a good therapeutic relationship and how this can be achieved
- What helps with developing a good therapeutic relationship, and the benefits of this

The project had two stages:

Stage 1 included recruiting patients with schizophrenia and psychiatrists from four European countries – Germany, Hungary, Poland, and Italy. Two treatment centres were identified from within each country, one urban and one rural.

Stage 2 included two focus groups with patients, psychiatrists and carers.

Patient and psychiatrist profiles

Twenty-eight patients and 28 psychiatrists took part in stage 1. Most patients were male (64%), aged between 41-50 years (39%) and had a relatively long length of illness of 16 years or more (46%). 42% of patients had seen more than five psychiatrists during their time in contact with psychiatric services, which averaged 28.5 years. Just under a third of patients (29%) had been seeing their current psychiatrist for more than 10 years, but for 14% this was less than a year.

57% of psychiatrists were female. Over half (57%) were above the age of 41 years. The average length of time practicing as a psychiatrist was 17.5 years. Psychiatrists typically saw an average of 15 patients a day. For stage 2, seven patients and two informal carers took part in the first focus group; and, eight patients and three psychiatrists participated in the second.

Patient experiences and perspectives

Patients described a mix of experiences when first diagnosed with schizophrenia. Just under a third had not had their diagnosis explained to them. Some reported it was not easy to comprehend a diagnosis of schizophrenia, or even accept it. Others received explanations about their diagnosis that helped them to make sense of their symptoms and behaviour.

For many patients, meeting their psychiatrist for the first time was a positive experience. Patients expressed many different hopes and expectations at this first meeting, including wanting to get better as soon as possible, to receive the right treatment/medication for them to recover and help in resolving practical problems.

Very few patients reported having a meeting with a psychiatrist that did not go so well. Some expressed times they did not want to talk during their meetings and this led to some tensions in the therapeutic relationship.

A good therapeutic relationship was described by patients as including acceptance, being listened to without judgement, humour, empathy, humility, patience, being good natured, courteous, and warm. Trust and being understood were other qualities in a psychiatrist patients felt underpinned a good therapeutic relationship.

There were times where the therapeutic relationship could be compromised. This was especially so if outpatient meetings were too infrequent or if the psychiatrist was very busy, tired and not able to attend to the patient well. Patient symptoms were another factor that could impact on the relationship.

Informal carers reported that their relationship with their relative's psychiatrist had changed for the better. Psychiatrists recognised the importance of family support.

The majority of patients had changed psychiatrists several times. Sometimes this was because they found it difficult to relate to them. The option to change psychiatrist was considered important.

Treatment decisions and how these were made varied; some patients were able to express their opinion about their treatment, others were not asked by their psychiatrist. This often depended on the circumstances (severity of symptoms, whether receiving hospital or outpatient treatment, etc.). However, half of all patients did have the opportunity to have their say regarding their overall treatment. Few patients received psychotherapy.

PSYCHIATRISTS' EXPERIENCES AND PERSPECTIVES

Most psychiatrists reported being excited, curious, calm and interested in the patient they were meeting for the first time. Psychiatrists reported their hopes and expectations and what they wanted for the patient. Some focused on building a good therapeutic relationship from the outset. Psychiatrists also focused on making the patient feel comfortable enough to talk about their symptoms.

Meetings that went well were usually when the patient's condition was stable. They would be better able to reflect and understand any difficulties and be open for discussion. Meetings would become more difficult, not only if a patient's symptoms deteriorated, but also if the psychiatrist was short of time or not listening. Sometimes discussions would also become tense if the psychiatrist and patient did not agree on a particular matter, usually medication.

On the whole psychiatrists described their relationship with their patient as good. They acknowledged however, that while there was reciprocal trust and positivity in the relationship there was always a chance this could change. Psychiatrists also agreed that qualities such as empathy, warmth, calmness and the ability to listen without judgement were important for a good therapeutic relationship.

When discussing medication many psychiatrists would propose treatments and, as much as possible attempt to make the decisions with the patient. This was felt to be important to ensure better adherence to medication.

All psychiatrists only talked to families with the patient's agreement first. Involving families or informal carers was important with helping to manage a patient's medication, any difficulties, and with providing feedback to psychiatrists. Improving families' awareness of the patient's condition/problems and receiving help, advice and support from psychiatrists were also vital.

CONCLUSIONS

The findings show the positive experiences patients wand psychiatrists can achieve when the therapeutic relationship is well established. There were few notable differences between countries and most treatment centres were similar in terms of patientpsychiatrist experiences, treatment and therapeutic relationships. This was largely explained by the way the participants were selected and the limited available data collected.

Practices in psychiatry have changed a great deal over the past two decades and our findings show how building trust with patients diagnosed with schizophrenia has moved forward in many ways. The inclusion of family or informal carers into patients' recovery and treatment is one example. Patients having their say in their treatment and care, is another. All of these form the basis of a positive therapeutic relationship, without which very little can be achieved. However, there is always more to be achieved, which includes redressing the balance between medication and psychotherapy, and the inclusion of recovery-oriented approaches and peer support workers into mental health services and standard practice.

BACKGROUND TO THE PROJECT

This report presents the findings and recommendations of a joint partnership project between GAMIAN-Europe and the European Psychiatric Association (EPA) to strengthen and improve the therapeutic relationship between patients and their psychiatrists, with a focus on patients diagnosed with schizophrenia.The project began in October 2021 and was completed in January 2023.

INTRODUCTION

Schizophrenia is a mental health condition in which people can perceive or interpret things differently to others. Symptoms of schizophrenia typically include hallucinations (hearing or seeing things that others cannot), delusions (unusual beliefs), muddled thoughts, loss of interest in everyday activities and avoiding other people, including friends.

Estimates of the lifetime prevalence of schizophrenia in European general population ranges from 0.3% to 1.5%, with an average of 0.5%.[1] Many people with schizophrenia living in high income countries benefit from continuous treatment and care[2]. However, it has been estimated that between 15% and 50% of people with schizophrenia do not receive adequate professional treatment[3].

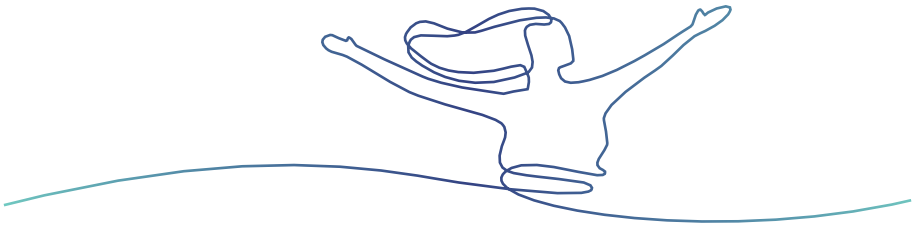
The majority of those that do receive some mental health care, obtain less than optimal care. It is also concerning that around 50% of people with schizophrenia discontinue treatment after their first or second appointment and up to 70% during later stages of care; all of which hinders their recovery [4,5].

The therapeutic relationship is crucial in the care process, especially for conditions that require long-term support for patients, such as schizophrenia[6]. When creating a positive experience of treatment and care establishing a therapeutic relationship between people with schizophrenia and their care team is therefore essential. This type of positive care experience relies on trust and mutual understanding, empathy, comprehensive information, good access to services and acceptable interventions, which are sustained over time.

Reports of patient experience in the literature are mostly through research carried out by professionals, such as psychiatrists and psychologists. These will include the use of questionnaires with rating scales designed and validated from a professional and social science framework perspective[7,8]. Many of these studies report satisfaction with care, although systematic assessments have only been conducted in countries with high investment in mental health. Many of the reasons for patients dropping out of care services and treatment trials have been attributed to patient characteristics[4,5].

However, there has been relatively little understanding of the care experience of people with mental health problems. Available data tends to be more anecdotal, often reporting negative experiences concerning misdiagnosis, over-prescribing, coercion, lack of information and no choice[8]. Such patient experiences can be summarized as an intense feeling of disempowerment and the absence of patient-centred care.

Mental health care can only be effective if patients and mental health workers can develop trust that will reduce fear and enable the establishment of a therapeutic relationship. This will require an understanding of each other's expectations, powers and limitations[9].



PURPOSE OF THE PROJECT

In view of the need to further understand the experiences of patients and their psychiatrists in terms of establishing a good therapeutic relationship we aimed to explore the perspectives of patients diagnosed with schizophrenia, and psychiatrists who treat and care for those with schizophrenia. More specifically, we aimed to understand from the perspective of patients and psychiatrists:

1. The positive and negative experiences of their therapeutic relationship
2. The interaction between patients and their psychiatrist
3. What facilitates a good therapeutic relationship and how this can be achieved
4. What helps with developing a good therapeutic relationship, and the benefits of this

WHAT WE DID (METHODS)

The project had two main stages of data collection. Stage 1 included recruiting patients and psychiatrists from four different European countries – Germany, Hungary, Poland, and Italy. Two treatment centres were identified from within each country, one urban and one rural. Representatives from each treatment centre were asked to recruit four patients and four psychiatrists for the project.

The following criteria were used to select participants:

Patients

- A diagnosis of schizophrenia for at least a year (ICD 10)[1]
- Age between 25 and 65 years
- Outpatients in a stable mental state
- In current contact with psychiatric services for treatment and/or care and with at least 4 contacts with a psychiatrist or admission to a psychiatric unit in the past year

Psychiatrists

- At least 3 years of working experience in clinical practice
- At least four days a week carrying out clinical work, which includes patients with psychosis

Ethical approval was received for each participating centre. Stage 2 of the project included two focus groups with patients, psychiatrists and carers to obtain feedback on the key findings from the first stage and to further explore the challenges, opportunities for establishing positive therapeutic relationships and to further assist with formulating recommendations for improving mental health services. Patient members of GAMIAN-Europe, relatives from EUFAMI and psychiatrists from the EPA were invited to take part in the focus groups.

Semi-structured questionnaires and topic guides for the workshops were developed for data collection. All qualitative data were analysed according to the themes interpreted from the data to address the key research questions. Quantitative data were summarised using frequencies and percentages.

WHAT WE FOUND

A total of 56 people - 28 patients and 28 psychiatrists - were recruited from the eight participating treatment centres for the project for stage 1. For stage 2, seven patients and two informal carers took part in the first focus group (three participants were from additional countries – Romania and Israel); and, eight patients and three psychiatrists participated in the second.[2]

PATIENT PROFILE

Patients recruited from the treatment centres were mostly male (64%) and many were aged between 41 -50 years (39%). Half of patients were unemployed.

Almost all had received a diagnosis of schizophrenia (96.5%) and many with a relatively long length of illness of 16 years or more (46%). 42% of patients had seen more than five psychiatrists during their time in contact with psychiatric services, which averaged 28.5 years.

Just under a third of patients (29%) had been seeing their current psychiatrist for more than 10 years, but for 14% this was less than a year.

TABLE 1

Patients' demographic and clinical profile – frequencies (n=28)

	n	%
Gender		
Female	10	36
Male	18	64
Age (years)		
20-30	5	19
31-40	6	21
41-50	11	39
51+	6	21
Employment		
Employed	10	35.5
Unemployed	14	50
Retired	3	11
Not known	1	3.5
Country of residence		
Germany	4	14.5
Hungary	8	28.5
Italy	8	28.5
Poland	8	28.5

	n	%
Diagnosis		
Schizophrenia	27	96.5
Schizoaffective disorder	1	3.5
Length of illness (years)		
1-5	3	11
6-10	2	7.5
11-15	6	21
16-20	7	25
21+	6	21
not known	4	14
No. of psychiatrists seen		
1-2	5	19
3-4	10	36
5+	12	42
Not known	1	3
Years in contact with psychiatric services		
median		28.5
min		1
max		46

TABLE 2

Psychiatrists' profile – frequencies and averages (n=28)

	n	%
Gender		
Male	11	39
Female	16	57
Not known	1	4
Age (years)		
20-30	1	4
31-40	11	39
41-50	8	28.5
51+	8	28.5

	n	%
Years practicing as a psychiatrist		
Median	17.5	
Min	3	
Max	35	
No. of patients seen on a typical day		
Median	15	
Min	2	
Max	42	

PSYCHIATRIST PROFILE

57% of psychiatrists were female. Over half (57%) were above the age of 41 years. The average length of time practicing as a psychiatrist was 17.5 years. Psychiatrists typically saw an average of 15 patients a day.

PATIENTS' EXPERIENCES AND PERSPECTIVES

Being diagnosed with schizophrenia

Patients described a mix of experiences when first diagnosed with schizophrenia. For some it was too long ago to remember, for others the experience was vivid. When asked whether their diagnosis had been explained to them, 28% reported no. Those reporting this were diagnosed before 2000.

> *'The psychiatrist didn't say anything about it …the psychologist said something about it, but I didn't get a detailed explanation.'*
>
> - Patient 8, male, aged 43, Hungary, urban

Some patients described being admitted to hospital at the time of their diagnosis.

'…at first they locked me up in a psychiatric hospital, gave me injections, strapped me in and no one talked to me....'

- Patient 18, male, aged 45, Poland, urban

Experiences like this would have been frightening and confusing. It was not always easy for a patient to comprehend a diagnosis of schizophrenia, or even accept it.

Others received explanations that helped them to make sense of their symptoms and behaviour. These were patients who were diagnosed in the past 10 years.

'It was explained to me… but I didn't really listen.'

- Patient 23, male, aged 45, Poland, rural

'At the time I didn't know what it meant despite the fact that the doctor talked about it, talked about treatment, prognosis, what could be done to improve it.'

- Patient 20, female, aged 35, Poland, urban

'The reason for my paranoia and why I had difficulties in relationships with others was explained to me'.

- Patient 9, male, aged 25, Italy, urban

'… [The psychiatrist] told me that schizophrenia is a chronic illness and that I can have good and bad moments, and that taking therapy could reduce the frequency of the bad moments.'

- Patient 11, female, aged 65, Italy, urban

MEETINGS WITH THEIR PSYCHIATRIST

Just over half of patients (54%) met their current psychiatrist in hospital. For many, meeting their psychiatrist for the first time was a positive experience.

'It was reassuring. I liked that they were being optimistic about my condition.'

- Patient 5, male, aged 42, Hungary, urban

Some patients, who reported being unwell at the time, experienced feelings of fear, agitation and anxiety.

Patients expressed many different hopes and expectations at this first meeting. These included wanting to get better as soon as possible, to receive the right treatment/medication for them to recover and help in resolving practical problems.

'In the beginning I was scared and I didn't feel comfortable. I felt like I was crazy and didn't want to talk with the psychiatrist.'

- Patient 14, female, aged 23, Italy, rural

'I hoped to feel better, to stop having strange ideas and to resolve everything in a short time.'

- Patient 11, female, aged 63, Italy, urban

One patient pointed to the importance of the therapeutic relationship. Being listened to and being understood was also important.

'I wanted to feel safe, to have someone next to me, to be able to trust that person, to not disrespect me and to listen to what I say.'

- Patient 2, female, aged 40, Hungary, urban

Others had few, if any expectations, but seemed pleased with how things had turned out.

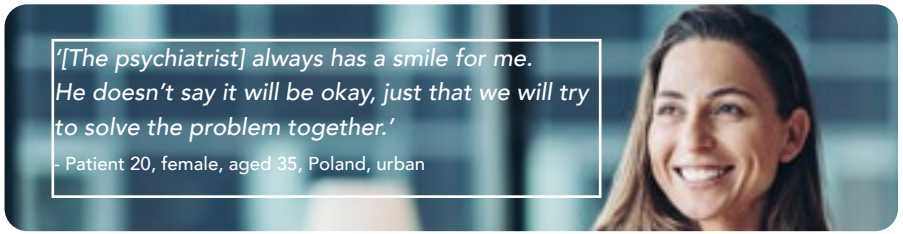
'I don't think
I had any expectations,
I was glad
[the psychiatrist] helped.'
- Patient 20, female, aged 35, Poland, urban

All patients felt comfortable enough to discuss anything with their psychiatrist. Discussions with their psychiatrist would often include several topics: how the patient is feeling (symptoms and mood), any concerns they might have, their daily routine, relationships, any problems they have encountered and medication.

> *'We start with small talk and I make some jokes and then we discuss more serious topics.'*
> - Patient 10, male, aged 27, Italy, urban

Very few found it hard to talk to their psychiatrist, but there were occasions when this happened. For example, if their 'voices' forbade them or if a patient found it difficult to express themselves.

Meetings for some patients were very regular, happening every few weeks, and ranged from 10 to 45 minutes with an average of 20-30 minutes. All patients described their meetings with their psychiatrist as positive. Sometimes patients needed reassurance when discussing stressful thoughts or difficulties since their last meeting.



For other patients, a meeting that is relaxed and where they leave feeling more confident and stronger was helpful. Meetings with their psychiatrist even became a source of stability in the patient's life.

> *'Usually our meetings are good. I feel like that they are a stable point in my life. They don't make me wait and if I have a problem they help me solve it.'* - Patient 3, female, aged 51, Hungary, urban

WHEN A MEETING DID NOT GO SO WELL

Very few patients reported having a meeting with a psychiatrist that did not go so well. Some expressed times they did not want to talk during their meetings and this led to some tensions in the therapeutic relationship.

> *'Sometimes I don't feel like talking and I would prefer that the visit doesn't last long. I am not sure why this happens.'*
> - Patient 11, female, aged 63, Italy, urban

Further tensions in the therapeutic relationship would arise if a patient was asked to do something they would prefer not to.

As described above involuntary admission to hospital was not always conducive to creating a good therapeutic relationship with a psychiatrist, and it was particularly important to manage these circumstances with care and compassion, especially if a patient continues to see the same clinician in their outpatient meetings.

> *'At our first meeting I didn't want to talk and she [the psychiatrist] insisted so I got upset.'*
> - Patient 14, female, aged 23, Italy, rural

THERAPEUTIC RELATIONSHIP AND QUALITIES OF A PSYCHIATRIST

Patients all reported having a 'good' relationship with their current psychiatrist. Some described this as 'harmonic', 'pleasant' and 'warm-hearted'. Humour was important for some patients, but also qualities such as being a good professional, honest and helpful. Listening was a reoccurring theme and central to a good therapeutic relationship. Being able to listen and understand a patient was considered important when forming the basis of a good therapeutic relationship.

> *'[My psychiatrist] listens to me, accepts what I say, and pays attention to me.'* - Patient 6, male, aged 40, Hungary, urban

From the patients' perspective, the qualities needed by a psychiatrist were varied but also indicated common themes such as empathy, patience, being good-natured, courteous, warm, a good listener, and humility. Trust was also important, as was feeling understood.

'[Good qualities of a psychiatrist] is someone trustworthy and stable, who I can count on and is able to help when I have a problem.'
- Patient 3, female, aged 51, Hungary, urban

'It is important to feel the problem of the person, to help everyone individually according to their own needs.'
- Patient 2, female, aged 40, Hungary, urban

Many patients reported what they thought created a positive therapeutic relationship with their psychiatrist. These qualities mirrored what they thought were important. The ability to be calming when the patient felt stressed or agitated was also felt to be valuable.

An informal carer from the first focus group commented on how the patient-clinician relationship over the last decade has generally changed for the better.

'Psychiatrists are now younger, more open, participate more, work with families. The old fashion ways are now gone. There is more awareness and openness with patients.'
- Informal carer 1, mother, Israel

Only two patients reported what can impact negatively on their therapeutic relationship. At times these were related to the patient's symptoms, for example when feeling unwell or withdrawn or simply those times when they found it difficult to disclose some things.

'I didn't tell [my psychiatrist] about my phobia… I only talk about this with my psychologist, the psychiatrist doesn't know about it.'
- Patient 8, male, aged 43, Hungary, urban

There were times where the therapeutic relationship could be compromised. This was especially so if outpatient meetings were too infrequent or if the psychiatrist was very busy, tired and not able to attend to the patient well. Despite this all patients reported having a good connection with their psychiatrist.

CHANGING PSYCHIATRIST

The majority of patients had changed their psychiatrist on numerous occasions (see Table 1). There are several reasons why this happens. For some patients, this was not unusual, especially if they have been in touch with mental health services for many years; some psychiatrists move to other services or are rotated elsewhere during their training. There are times, however, when patients and psychiatrists do not always connect, especially where medication was concerned.

Two patients and an informal carer in the first focus group described their reasonsn for changing psychiatrists. One patient explained how she felt she was being prescribed, 'too much medication.'

A carer noted how it was important for them all (the patient, psychiatrist, and carer) to agree on important matters, such a diagnosis, treatment and the patient's accommodation.

The general agreement was to give yourselves some time to build a good therapeutic relationship or find another psychiatrist if necessary.

'You can improve your relationship with your psychiatrist, but if the trust is not there change psychiatrist! Part of the process is to find one that you get along with.'
- Patient, focus group 1, France

One carer felt the option to change psychiatrist also should be made available if relations do not improve over time.

MAKING DECISIONS ABOUT TREATMENT

A good therapeutic relationship is fundamental to the way in which treatment is decided and adhered to by the patient. If the relationship is built on trust patients may be more likely to engage with their treatment. All patients received psychotropic medication - antipsychotic medication or anxiolytics. A small number received depot injections.

Six patients from Hungary reported receiving a combination of medication and psychotherapy, and one received occupational therapy. In addition to this, some patients reported learning relaxation techniques with a psychologist and receiving medication to help them sleep at night.

All psychiatrists reported prescribing medication for their patients with schizophrenia, six of whom also received psychotherapy (three in Hungary, and three from Germany).

A further six psychiatrists also reported providing supportive management or therapeutic talks to patients. This was likely to involve education, problem solving, and reassurance.

How these treatments were decided and the extent to which patients were able to have their say varied hugely. Some were able to express their opinion about their treatment, others were not asked by their psychiatrist.

Often the treatment received was a journey of exploration to identify which medication appeared to work well for the patient, and with minimal side effects. Finding this balance can take time.

It is not unusual for different medications to be trialled and then to be changed or the dose adjusted, which can take several months and sometimes years.

Not all treatment decisions were shared between the patient and their psychiatrist. This often depended on the circumstances (severity of symptoms, whether receiving hospital or outpatient treatment, etc.).

> *'I used to have electroshock [treatment]. I was hospitalized many times for psychosis. Treatment was discussed with me but only when I was admitted to the hospital. I was given medications and I didn't know what.'*
> - Patient 20, female, aged 35, Poland, urban

There are times when treatment decisions are one-sided, in which the psychiatrist decides what treatment might be best for the patient without asking their opinion. A small minority of patients reported this experience.

> *'The power difference between a psychiatrist and a patient is huge. [In hospital] psychiatrists will think they are 'king of the world' and can be less cooperative. When a patient is more stable and seen in an outpatient clinic, there's a difference again.'* - Informal carer 1, mother, Israel, focus group 1

One informal carer from the first focus group highlighted the difference in the patient-clinician power relationship in hospital compared to outpatient meetings.

One patient was reluctant to take their medication via depot injections, as suggested by their psychiatrist.

> *'I did not really want these injections, but I agreed for peace of mind; my mother wanted them and the psychiatrist did too.'*
> - Patient 18, male, aged 45, Poland, urban

However, half of all patients did have the opportunity to have their say regarding their overall treatment.

> *'The psychiatrist recommended the medication and also mentioned the psychotherapeutic option; we were able to decide in agreement whether I wanted to take therapeutic treatment in addition to the medication.'*
>
> - Patient 5, male, aged 42, Hungary, urban

FAMILY, FRIENDS AND SUPPORT NETWORKS

All patients had links with family members and/or friends who supported them to some extent. Not all support networks were extensive, some patients reported only having contact with one close relative (a parent or a sibling), with very few, if any friends. For some patients relationships with family could be difficult.

> *'[I have a] son, but I don't trust him. A caregiver comes, he pays her. All in all she is good…and drives me to the doctor.'*
>
> - Patient 19, female, aged 35, Poland, urban

A few patients were able to live independently, but some needed support with day to day living and maintaining their treatment regime. Usually, the support was from a parent.

Communication between an informal carer (family member, friend or close other) and the patient's psychiatrist is also important to consider as part of the therapeutic relationship. Discussions between an informal carer and the patient's psychiatrist must only take place if the patient agrees to this.

> *'I am happy for this. In the beginning I wasn't sure, but then I decided to allow them to come in and to talk with the doctor.'*
>
> - Patient 9, male, aged 25, Italy, urban

PSYCHIATRISTS' EXPERIENCES AND PERSPECTIVES

Meetings with patients

Psychiatrists described many different feelings when first meeting a new patient. For many this initial meeting was fairly typical; usually a referral from a General Practitioner or a colleague. For one psychiatrist it was still a relatively new experience.

> *'This was one of the first patients I came to treat, so I had many doubts and concerns. I was stressed and curious.'*
>
> - Psychiatrist 22, male, aged 31, Poland, urban

For others, it was a tense or difficult first meeting, especially if the patient was very unwell.

> '[The patient] was inhibited, their appearance was neglected, they spoke softly and very slowly. I found it difficult because of the communication problem.'
>
> - Psychiatrist 13, female, aged 36, Hungary, urban

Most psychiatrists reported being excited, curious, calm and interested in the patient they were meeting for the first time. Psychiatrists reported their hopes and expectations and what they wanted for the patient. Some focused on building a good therapeutic relationship from the outset.

> *'I hoped to build a good therapeutic relationship and alliance to reduce [the patient's] symptomatology and to improve his day to day functioning'.*
>
> - Psychiatrist 5, male, aged 34, Italy, urban

Psychiatrists also focused on making the patient feel comfortable enough to talk about their symptoms. They tried to decide how best to motivate them and to gain their cooperation with medication and ways to improve their quality of life.

The topics discussed in meetings were varied. Most centred on discussions concerning emotional states, symptoms and medication, family relationships and activities.

> *'I hoped to be able to activate the patient and motivate them to participate in everyday activities.'*
>
> - Psychiatrist 15, male, aged 71, Hungary, urban

Some were in the form of a clinical interview to assess psychiatric and physical health. Each psychiatrist had a similar approach to how they obtained the information they required, usually by letting the patient start the conversation and then asking their questions afterwards.

> *'We discuss topics that the patient would like to discuss and I ask concrete questions about their current state of affairs.'*
>
> - Psychiatrist 1, female, aged 38, Germany, urban

Acknowledging any progress was also a key feature for some meetings; sometimes the psychiatrist would note this in meetings or the patient would point it out.

'I am always pleased to acknowledge the progress [the patient] reports.'

- Psychiatrist 6, male, aged 48, Italy, urban

The time a meeting took also differed, some were short, about 15 minutes, others 60 minutes if more difficult situations needed to be discussed.

Meetings that went well were usually when the patient's condition was stable. They would be better able to reflect and understand any difficulties and be open for discussion.

Meetings would become more difficult, not only if a patient's symptoms deteriorated, but also if the psychiatrist was short of time or not listening.

Sometimes discussions would also become tense if the psychiatrist and patient did not agree on a particular matter, usually medication.

'[The patient] expressed their displeasure about their medication. Although we reached some kind of consensus, the conversation did not end with a good feeling…I later felt I had "forced" my opinion on them, perhaps due to my excessive concern…'

- Psychiatrist 19, male, aged 42, Hungary, rural

THERAPEUTIC RELATIONSHIP WITH PATIENTS

On the whole, psychiatrists described their relationship with their patient as good. They acknowledged however, that while there was reciprocal trust and positivity in the relationship there was always a chance this could change.

'It is a very good relationship, but always susceptible to break.'

- Psychiatrist 10, female, aged 62, Italy, rural

One psychiatrist noted the difficulties they experienced in building a therapeutic relationship, recognising that it can be hard.

'[Building a therapeutic relationship] can be drawn out and difficult. I often feel that I am more motivated than them [the patient] to change. I am working on being able to accept the limitations.'

- Psychiatrist 13, female, aged 36, Hungary, urban

A mutual understanding, humour and acceptance of each other provided a way forward. One psychiatrist described what they had discovered.

'The most important thing is attention, patience and empathy… and willingness to compromise.' - Psychiatrist 17, female, aged 35, Hungary, rural

This demonstrates the flexibility needed by the psychiatrist, for example by not imposing their point of view too heavily, especially if the patient does not agree.

Understanding the patient's point of view and valuing them as a person were other important qualities.

'[It's important] to take the patient seriously and to perceive him/her as valuable.'

- Psychiatrist 4, female, aged 31, Germany rural

Some psychiatrists noted the importance of setting limits or boundaries with the patient, but also creating a sense of security to build a trusting relationship.

'I consider transparency to be important by establishing boundaries and … that important issues are always discussed in a secure relationship...'

- Psychiatrist 18, aged 33, Hungary, rural

While some psychiatrists reported the importance of being professional, many others emphasised qualities such as empathy, warmth, calmness and the ability to listen without judgement.

These same qualities were reiterated when psychiatrists were asked what they thought created a positive therapeutic relationship.

While all psychiatrists reported feeling comfortable talking to their patients some described times when it was difficult to discuss some subjects or issues.

'I don't always feel comfortable to discuss [some things], but I do it anyway.'

- Psychiatrist 23, female, aged 52, Poland, urban

There were occasions when patients' symptoms made conversations a little more challenging.

'I don't feel I can talk to the patient when they have excessive fears and worries. It takes so much time to ease them, and we have a harder time to address their causes.'

- Psychiatrist 19, male, aged 42, Hungary, rural

For the most part, psychiatrists were able to talk to their patients, even during difficult times. The key was to help them feel secure and relaxed.

Most psychiatrists noted the good connection they had with their patients, and that they knew them well. They also felt their patient listened and understood them.

'[My] patient listens. He can weigh things up, decide for himself and knows which risks he wants to expose himself to and which not (e.g. changing medication).' - Psychiatrist 4, female, aged 31, Germany, rural

When asked if there was anything that could improve the therapeutic relationship with their patient psychiatrists listed a broad spectrum of things - more time to get to know the patient well and to understand their situation better, more outpatient visits with them and their family to improve relations, provide more positive feedback on progress, develop access to psychotherapy, rehabilitation and supported employment, and more training and discussion of their cases with other clinicians (e.g. a Balint group).

Psychiatrists participating in the second focus group talked about some of the patients they had been seeing long-term. One reflected on what they know now, as an experienced psychiatrist, compared to when they had just started practicing.

> *'Now it's a bit easier because I have more experience. I have more information about what can happen. When I was young, I was more hopeful and full of ideas...it can be hard at the beginning.'*
>
> - Psychiatrist A, Poland, focus group 2

> *'I'm much better now at establishing a therapeutic relationship because I'm more eager to establish it from person to person. Before it was much more 'doctor-patient' level and more controlling…which was wrong.'*
>
> - Psychiatrist B, Croatia, focus group 2

Another experienced psychiatrist described how he established trust and the first hour of meeting a new patient is the most important.

> *'I have had one patient for 22 years. [When I first met him] he was suicidal. It took more than an hour to understand what the real problem was. He always remembers this. That is the key to building trust and to maintaining it.'*
>
> - Psychiatrist C, Germany, focus group 2

Maintaining the therapeutic relationship is even more important. When conflict might arise, one psychiatrist saw this as a positive thing in which to grow and learn more.

> *'Conflict gives you the opportunity to resolve the situation. When you resolve this conflict you learn something and part of the relationship is about resolving conflict. It gives stability to the therapeutic relationship.'*
>
> - Psychiatrist B, Croatia, focus group 2

TREATMENT AND CARE

Along with prescribing antipsychotic medication many psychiatrists reported providing supportive care. While this was not described in detail, two psychiatrists provided psychotherapy. In addition to medication, psychiatrists also provided what they described as supportive or therapeutic talks or conversations and education about their condition. One psychiatrist was actively supporting their patient find employment.

All psychiatrists reported they proposed and discussed medication with the patient. The extent to which patients were involved in deciding their medication varied. Often the psychiatrist would suggest what they thought would work for the patient. These suggestions were based on many things – the patient's current symptoms, previous medication and hospitalisation, medication side effects, the patient's life situation and the effectiveness of the medication itself (e.g. how well it worked).

> *'We decide together about medication. I try to describe all the advantages but also possible side effects of the treatment. The patient always agrees to the treatment.'*
>
> - Psychiatrist 21, female, aged 57, Poland, urban

Some psychiatrists continued with the medication prescribed by the patient's previous psychiatrist, making adjustments as necessary. Some psychiatrists recognised that patients were the ones taking the medication so it was essential to ask what they thought.

> *'I consider it important to take into account the patient's experience… since they are the ones receiving the medicine.'*
>
> - Psychiatrist 18, aged 33, Hungary, rural

Some psychiatrists felt it was important to involve the patient in treatment decisions to help ensure they would take their medication regularly. One psychiatrist reported how their patient understood the importance of taking their medication and the consequences of not doing so.

Another psychiatrist reported initial problems with medication compliance and noted how this had been resolved with depot injections which the patient had agreed to. Very few psychiatrists reported making treatment decisions without asking the patient's opinion.

It is also important for patients to be made aware of the implications of replacing any medication, and that this involves reducing or withdrawing slowly from any existing ones before replacing this with a new one. These changes can lead to new side effects or even relapse if not carried out appropriately, so on-going, two-way discussions are essential.

INVOLVING FAMILY MEMBERS IN MEETINGS

> *'I talk to family members in agreement with the patient. I think it is very important to create a valid network to support the patient, especially with the people close to them in daily life.'*
>
> - Psychiatrist 7, female, aged 49, Italy, urban

All psychiatrists only talked to families with the patient's agreement first. There were times when the patient would request meetings with close family or when the psychiatrist suggested that close family (a parent, spouse, sibling or friend) join them to discuss their diagnosis, treatment, and/or ongoing care.

Some families were kept informed even if they did not attend meetings, but this was always with the patient's prior permission. Involvement of close family or informal carers, as one psychiatrist pointed out, can help with the patient taking their medication.

> *'When the patient was less adherent with their medication, I deemed it necessary, after agreement with the patient, to involve family members to help.'* - Psychiatrist 8, female, aged 33, Italy, urban

Some psychiatrists also involved families to help with managing any difficulties, but one noted that some family relationships were quite complex.

Psychoeducation for family members was seen as important, not only to know how best to support the patient, but to also have an understanding of the patient's diagnosis and prognosis. Improving families' awareness of the patient's problems and condition was important.

Families were also helpful in providing feedback to psychiatrists.

> *'Talking to close relatives is an important part of working with the patient. The family is almost always very helpful, if available.'*
> - Psychiatrist 21, female, aged 57, Poland, urban

One informal carer from the first focus group noted, psychiatrists are now usually willing to speak to carers and building the family-clinician relationship is an important thing for two main reasons.

> *'The family needs advice and input from the psychiatrist [about the patient]. The family also need healing too'*
> - Informal carer 2, mother, Romania, focus group 1

PRESSURES AND CHALLENGES

Psychiatrists described a number of pressures they encountered when working with patients. These were wide-ranging, but were broadly split between concerns regarding their patient, such as managing their distress, substance use, symptoms (extreme inhibition, slowness and cognitive difficulties), and/or side effects of medication.

The challenges relating to psychiatrists' own development and learning included areas such as finding appropriate communication strategies, managing family expectations and ways to build patient trust. One psychiatrist, however, pointed to system challenges which added to the pressure of their work, such as the high volume of paperwork, underfunding of psychiatry and organisational difficulties.

DISCUSSION

A diagnosis of schizophrenia can be a daunting experience, and the onset of psychosis is invariably a frightening experience for patients and those close to them. For some it led to an involuntary admission to hospital where they were restrained and given medication without choice. Such admissions are based on specific mental health legislation that exists in many European countries. However, it does not make the experience for all those involved at all easy, especially for patients.

The experiences of patients charted in this report are generally very positive, and likely to be a result of how patients and psychiatrists were recruited for the project. Patients and psychiatrists nearly all described the good therapeutic relationships they had. These experiences, however, do not represent the full range of experiences that many patients with schizophrenia encounter, which can be negative.

The focus group with patients and carers, however, did reveal some of the reasons why patients may frequently change their psychiatrist; usually because they would like a clinician who listens and understands them. Not every patient and their family are able to search for the 'right' psychiatrist. This often depends on the mental health services available to them and if any choice in clinician is offered. Some services are better resourced than others, especially those within urban areas compared to rural ones.

Mental health services also differ enormously within and between European member states; some have better community provision than those still heavily reliant on hospital-based care.[10]

There appeared to be few obvious differences in the treatment and care either within or between participating countries, which again is very likely to do with the samples selected and the limited available data for the project.

Germany, Poland, Hungary and Italy vary significantly in terms of their mental health care services. However, patients that did report negative experiences at the time of first being diagnosed had these more than 20 years ago. These were patients from Hungary and Poland and received inpatient treatment from psychiatric hospitals based in urban areas.

A key similarity between all centres and countries is the focus on psychotropic medication, with few patients receiving psychotherapy or other psychosocial approaches. There was little, if any, reference to the use of recovery-oriented approaches.

These approaches move beyond traditional treatment strategies towards a journey of recovery that includes, among many things, reconceptualising illness, hope, empowerment and building on a patient's strengths.[11]

Part of this includes emotional, social and practical support from peers; in which people use their own experiences to help others with similar experiences.

The inclusion of peer support workers is becoming increasingly important to include within the mental health workforce.[12] Among the many benefits of peer support workers is improved adherence to medication and healthful behaviours (e.g. taking exercise).[13]

Treating patients with compassion and kindness is something that every service can strive for, and importantly, provides an important basis on which to build trust and to help patients engage with treatment and care. Fortunately, many patients reported having a positive experience when meeting their psychiatrist for the first time.

Offering reassurance to a patient diagnosed with schizophrenia appeared important at the early stages of developing trust and a good therapeutic relationship. Interestingly, the hopes and expectations of both patients and psychiatrists were similar. Each wanted to see an improvement in symptoms as quickly as possible.

Psychiatrists were keen to seek the patient's cooperation with treatment and to visit them when arranged. Patients wanted to be listened to without judgement, be taken seriously and to feel comfortable enough to talk about anything. For the most part psychiatrists knew this and aimed to include it in their clinical practice.

All patients and psychiatrists in the project had established a good therapeutic relationship. Qualities such as being warm-hearted, empathetic, pleasant, accepting any limitations and fundamentally being a good listener were important qualities for a psychiatrist, as far as patients were concerned.

There were times when the therapeutic relationship was tested during difficult discussions, and sometimes hindered by the patient becoming unwell or time constraints for psychiatrists, but this was never long-lasting.

Having the time to get to know each other seems an obvious way to establish a good therapeutic relationship, but is not always easy to do in practice. While many patients and psychiatrists had known each other for some time (years in some cases) some had only know theirs for a few months.

Even in this relatively short period of time a good therapeutic relationship is possible. A mutual understanding of each other, openness and empathy help. Once trust and a therapeutic relationship have been established work to maintain this was even more important, especially when negotiating treatment options.

Treatment, particularly medication was a critical part of the therapeutic relationship and seeking the patient's opinion about medication after explaining all the advantages and disadvantages of the available options is essential.

Very few psychiatrists took unilateral decisions about medication which shows how clinical practice is moving towards making joint decisions with the patient about treatment.

It can be difficult for a patient to be fully informed about the best treatments for schizophrenia and it is unsurprising that patients will leave these decisions to their psychiatrist who specialises in this. However, it is becoming increasingly more important for patients with a mental health condition to be better informed about available treatments and to be asked what they think when a psychiatrist recommends or suggests a treatment plan for them.

Involving close family or informal carers who provide support as part of the therapeutic process is important, but only if the patient agrees beforehand and finds it beneficial. Psychiatrists appeared to see the benefit of ensuring social and familial support for the patient.

CONCLUSIONS

The project yielded insightful experiences concerning trust and therapeutic relationships between patients, informal carers and psychiatrists – how these were established and the importance of maintaining them. The focus groups confirmed many of the findings obtained from the eight treatment centres.

The findings show the positive experiences patients and psychiatrists can achieve when the therapeutic relationship is well established. There were few notable differences between countries and most treatment centres were similar in terms of patient/psychiatrist experiences, treatment and therapeutic relationships. This was largely explained by the way the participants were selected and the limited available data collected.

Practices in psychiatry have changed a great deal over the past two decades and our findings show how building trust with patients diagnosed with schizophrenia has moved forward in many ways. The inclusion of family or informal carers into patients' recovery and treatment is one example. Patients having their say in their treatment and care is another. On the surface, these changes seem small but they are momentous.

All of these form the basis of a positive therapeutic relationship, without which very little can be achieved. However, there is always more to accomplish, which includes redressing the balance between medication and psychotherapy, and the inclusion of recovery-oriented approaches and peer support workers into mental health services and standard practice.

RECOMMENDATIONS

Based on the project's key findings we suggest the following recommendations to continue further improvements to the provision of mental health care and treatment.

FOR PSYCHIATRISTS AND OTHER MENTAL HEALTH PROFESSIONALS TO:

- Receive continued support and training to ensure they are able to develop and maintain a good therapeutic relationship for patients with schizophrenia
- Offer patients the option to change psychiatrist if they no longer find the relationship beneficial
- Continue supporting patients and involving families as appropriate by exploring best practices and other promising approaches to enhance patient outcomes
- Ensure families and informal carers receive the best possible support for their own wellbeing
- Continue to explore best practices to minimise patients' negative experiences when admitted on a compulsory basis to hospital

FOR PATIENTS TO HAVE:

- Access to recovery-oriented approaches and peer support workers to enhance their journey of recovery alongside standard mental health care and treatment. This will provide enhanced benefits to patients', including adherence to treatment and additional support
- Increased access to psychotherapy. The emphasis on medication for the treatment of schizophrenia needs to be redressed to ensure patients are also able to redeem the benefits of psychotherapy
- More information about their treatment so that they are able to make informed choices about the treatment they are offered. This can enhance conversations between patients and psychiatrists and ensure better shared-decision making

FOR POLICY MAKERS AND SENIOR MENTAL HEALTH PROFESSIONALS TO:

- Ensure mental health services receive enough resources to continue professional training, support and development based on improving therapeutic relationships with patients
- Begin working towards broadening mental health workforces to include peer support workers. Peers are becoming an important addition to mental health services. Opening up training and employment opportunities for people with lived experience of mental illness is a win-win situation. It is an important way to modernise mental health services and deliver recovery-oriented approaches
- Offer psychotherapy and recovery-oriented approaches as standard These can be combined where appropriate to ensure greater reach to those who may reside in areas which are under-resourced or where mental health professionals and/or peer support workers are in short supply[14]
- Further invest in inpatient wards to ensure these are safe and agreeable environments for patients experiencing a psychotic episode

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