

EMPIRICAL STUDY

A need for “good eyes”: Experiences told by patients diagnosed with psychosis

INGA TIDEFORS, Associate Professor & ELISABETH OLIN, PhD

Department of Psychology, University of Gothenburg, Gothenburg, Sweden

Abstract

This study highlights experiences of psychiatric care described by patients diagnosed with psychosis. The aim was to investigate how patients, based on earlier experiences, described their wishes and needs regarding the psychiatric care system. Data comprised material from four focus groups; analysis used an inductive thematic approach. Relationships with staff emerged as a recurring theme. During periods of psychosis, patients needed staff to act as “parental figures,” providing care, safety, and help in dealing with overwhelming stimulation from the outside world. In the ensuing struggle to devise a livable life, the need for relationships recurred. In this phase, staff needed to give their time, provide support through information, and mirror the patient’s capacity and hope. The patient’s trials were described as threatened by a lack of continuity and non-listening professionals. It was important for staff to listen and understand, and to see and respect the patients’ viewpoints.

Key words: *Relationship, respect, patient experiences, psychiatric care, thematic analyses*

(Accepted: 2 December 2010; Published: 13 January 2011)

Introduction

Understanding of the patient’s experience of psychiatric care is urgently needed. Earlier studies demonstrate that deciding to seek help from the psychiatric care system is, for many individuals, a process characterized by a fear of receiving inadequate help. This could include a fear of receiving coercive care or inadequate medication, which, in turn, could lead to an aversion to seeking necessary care (Segal, Hodges, & Hardiman, 2002). In another study, slightly fewer than half of 142 surveyed patients report having been to a psychiatric unit to which they would never choose to return (Grubaugh, Frueh, Zinzow, Cusack, & Wells, 2007). Most surveyed patients with a distressing experience of psychiatric care do not communicate this to the staff, and only one-fifth report that a staff member asked about their negative experiences in the psychiatric care setting; such negative experiences could include loss of control in combination with unwanted medication, being with patients perceived as “scary,” witnessing “takedowns” of other patients, being put into

restraints, and being assaulted by patients and staff (Grubaugh et al., 2007). Since individuals with severe mental illness experience, as a group, high rates of traumatic events in their lifetimes, negative experiences of the psychiatric care system could bring back memories of earlier life traumas (Grubaugh et al., 2007).

The working alliance between patients and staff, and probably the effectiveness of treatment, is related to the degree to which the treatment takes patient expectations into consideration. Consequently, patient views must be considered when establishing a therapeutic relationship (de Haan, Peters, Dingemans, Wouters, & Linszen, 2002). In the early period of this field of study, Balint (1972) focused on the necessity for doctors of being more self-aware if they were to help their patients more effectively. He also advised doctors to act as “teachers”: the doctor should have a special understanding of the patient and of the complexity of his or her problems, and he should share this understanding with the patient. However, needs are often assessed differently by clients and mental health professionals,

both in terms of number of unmet needs and their nature (Hansson & Björkman, 2005). Disagreements in the area of unmet needs are crucial, since unmet needs are strongly associated with quality of life, though they are strongly resistant to changes in service delivery (Eisen, Dickey, & Sederer, 2000). Thus, patient needs risk being neglected (Slade, Leese, Taylor, & Thorncraft, 1999).

Some authors suggest that psychiatric institutions, especially psychiatric hospitals, cause more harm than good (Chee, Ng, & Kua, 2005; Liggins & Hatcher, 2005; Verehaege & Bracke, 2007), while others highlight the contradictory effects that psychiatric institutions can have on patients. On one hand, these institutions offer mental health treatment and a sense of belonging, which often increases the patient's quality of life. On the other hand, being an inpatient in a psychiatric care institution is linked to negative attitudes and devalued self-identity (Corrigan 2004; Ekeland & Bergem, 2006; Vogel, Wade, & Haake, 2006). Some studies state that even mental health providers can have negative attitudes towards people with mental illness (Barnes, 2000; Rogers & Kashmina, 1998; Sadow & Ryder, 2008; Servais & Sanders, 2007). Seeking and receiving psychiatric treatment is clearly associated with stigmatization, which could lead to decreased willingness to seek mental health care on the part of those needing psychiatric treatment (Corrigan & Lundin, 2001; Golberstein, Eisenberg, & Gollust, 2008; Vogel et al., 2006). Another hindrance to seeking care is the patient's unwillingness to discuss distressing matters, in order to avoid painful feelings.

A number of studies demonstrate that some of the key obstacles to participation are stigmatization, limited cognitive abilities, side effects of medication, mental illness severity, and lack of motivation (Finfgeld, 2004; Linhorst, Hamilton, Young, & Eckert, 2002). Other obstacles are hierarchical organizations, staff that resist change, paternalistic attitudes, and unwillingness to allocate power (Linhorst et al., 2002).

The aim here was to investigate how patients, based on earlier experiences, described their wishes and needs regarding the psychiatric care system.

Method

Material and participants

The material consisted of transcripts from four focus groups with adults diagnosed with a psychotic disorder; two groups included three participants each, one group included four, and another group five participants. Four men and 11 women ranging from 20 to 45 years old participated, all of whom

had experienced both inpatient and outpatient mental health care. At the time of data collection, the participants were patients in an open psychiatric care unit that specialized in treating individuals with various psychotic disorders. This unit also included a ward that permitted short-term inpatient care; most participants had experienced such care in that ward.

Focus group methodology

Focus group methodology is recommended when interviewees have limited power and influence over their life situations, which is often the case for individuals diagnosed with psychotic disorders. Being among others in a non-threatening and informal environment allows participants to express their own thoughts and feelings (Morgan, 1998). This method entails a number of participants discussing a predetermined topic in a session run by one or two moderators. Focus group methodology relies on discussion between participants and on moderator skill to encourage participants to talk freely (Puchta & Potter, 2004).

A focus group can be characterized as an open conversation, sometimes supported by a question guide that, in this study, consisted of open-ended questions about the participants' own experiences of psychiatric care. The groups were led by the two authors. In our role as moderators, we concentrated on being good listeners, on nonjudgementally encouraging each participant to share his or her experience, and on capturing the essence of the discussion. To deepen the discussion, we posed questions such as "Could you explain what you meant by ...?" Participants were allowed to present new perspectives and themes in the sessions.

After an introduction concerning ethics and informed consent, all participants were asked, one at time, to talk about their experiences of mental health services. Some participants were eager to talk, while others were more cautious; after a while, however, the ice was broken and the participants spoke freely.

At the end of each focus group, questions were asked about the experience of having taken part in the group, and participants were urged to contact the authors afterwards if they had any further questions.

Procedure

The participants were recruited with the help of a counselor at an open psychiatric care unit specializing in treating individuals with psychotic disorders. In addition to a psychotic diagnosis, the selection criteria included having regular, ongoing contact with this

psychiatric unit. The counselor informed the participants about the aim of the study and about what taking part would entail; the voluntary nature of participation was emphasized.

The focus groups took place in a calm and separate room in the open psychiatric care unit that the participants knew well. The sessions lasted between 2 and 2.5 h, were recorded, and transcribed verbatim (although the final transcripts were slightly edited in the interest of readability). To create an inviting atmosphere, the participants were served sandwiches and coffee. Each group session began with one author clarifying the purpose of the study and emphasizing that participation was voluntary; the format for the day's focus group was also presented. Participants then signed the informed consent form.

The study design was approved by the Regional Ethical Review Board, Sahlgrenska Academy, University of Gothenburg (Dnr 631-08).

Analysis

The transcripts were analyzed using inductive thematic analysis in a “data-driven” or “bottom-up” manner in which the material itself generated concepts and themes (Braun & Clarke, 2006).

The transcripts were first read and reread by both authors separately in order to grasp what was said about the main research question, i.e., the participants' experiences, wishes, and needs related to psychiatric care. The transcripts were then coded without trying to fit data into a preexisting frame and a list of ideas was noted. These ideas were discussed and then used in coding the dataset, with the aim of covering the whole dataset. Recurring patterns revealed various participant needs, some fulfilled by psychiatric care and others not.

In the next step, the authors separately went through the transcripts, sorting the codes and mapping various main themes in relation to the broad definition of needs. These themes were subsequently compared and discussed, and consensus was reached about two main themes. The first concerned basic needs and was labeled “Being looked on with ‘good eyes’.” The second theme concerned what the participants needed to control their own lives, and was labeled “Standing on one's own.” In organizing the data extracts into the two themes, sub-themes were created to provide structure to the themes. The extracts exemplifying each theme were organized mainly according to positive versus negative experiences. Although the focus group method entailed spontaneous participation that jumped from subject to subject, the subsequent analysis let us structure the dataset according to a time perspective, i.e., the

process leading from acute psychosis to relief of symptoms. Thereafter, all extracts were discussed in relation to the identified themes, controlling for the fact that the meaning was not displaced. Finally, the extracts were reviewed once again to choose the examples that best captured the essence of each theme and sub-theme.

Results

The themes and sub-themes are presented along with explanations, summaries, and quotations that demonstrate the relationship between data and themes. An overview is presented in Figure 1. The quotations were edited and abbreviated in the interest of readability; “/.../” indicates that the preceding and subsequent portions of the quotation come from different parts of the transcript but are uttered by the same participant.

Being looked on with “good eyes”

In both the acutely psychotic and in non-psychotic periods, relationships figured as a reoccurring theme. During psychotic periods, the need to be taken care of was prominent, while during recovery, it was important to be seen as a competent person. Statements expressing the desire to be perceived as an ordinary human being and not just a patient were recurrent. A prerequisite for being seen as an ordinary human was to be seen by the staff with “good eyes” and to be mirrored by significant others. “Good” mirroring strengthened the participant's sense of self, while “bad” mirroring posed a threat to the self and resulted in uncertainty about one's dignity.

Take care of me. Especially during acute psychosis, feelings of horror were present and it was hard to know what belonged to the inner versus the outer world. Participants expressed a need for safe relationships, including a need for help regulating stimulation from an overwhelming outside world, and a need to be mirrored by good eyes. Patients also needed to be taken care of in concrete ways; in this, the staff served as trustworthy caretakers, and such relationships with staff were a prerequisite for feeling safe.

The possibility of returning to known places and people, so participants could rest and have their basic needs satisfied, gave an opportunity to feel safe, to rest, and to find themselves.

When you come to this place ... everything calms down, it's a small unit, warm and cozy /.../ I was able to sleep, to rest, and to find myself.

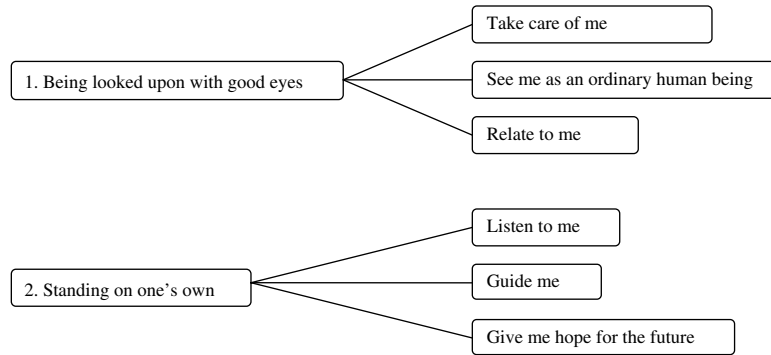


Figure 1. Themes and sub-themes.

A lack of relationships and an unpredictable environment were aspects that could negatively affect symptoms and were often experienced by participants as inpatients. In such situations, participants became unable to regulate external stimuli and risked being overwhelmed.

You are so scared during the psychosis ... the unknown, new faces, new personnel to relate to. When you thought in a wrong way ... the psychosis became more and more severe.

See me as an ordinary human being. It is well known that being a psychiatric patient can result in stigmatization. For example, the participants asked whether they or the staff members had the preferential right of interpretation. Consequently, a recurring theme was a struggle over how to behave towards the staff to avoid being regarded as mentally ill. A longing to be treated just like anybody else, by both staff and others, was frequently expressed by participants.

Trying to see oneself as a competent individual could be seen as a struggle against a sense of inferiority. A staff member might sometimes help the individual to see behind the psychiatric diagnosis, which reduced feelings of stigmatization and perhaps turned mistrust into trust.

My psychologist says that she doesn't put much emphasis on it, because diagnoses are only words ... don't really explain much about a person. More a medical term really ... you have to look at it that way.

The wish to be seen as an ordinary human being was also reflected in how the participants introduced themselves to each other at the start of the focus group, when they commonly described themselves as leading "normal" everyday lives. This may reflect a wish that life had a meaning unrelated to that of being a patient and, consequently, a hope that others would see them as ordinary human beings. One way of introducing oneself was to tell others about

present and former work or studies, and about hobbies.

Had a job in the social service. Now, just at home with my baby, work some weekends, go to the gym. Sometimes I write poems, or in my diary.

Some seemed to have an identity built on earlier traumas and contacts with psychiatric care. During the initial presentation in one focus group, one man described himself in a somewhat objectifying way, perhaps indicating that psychiatric care was his primary context: "Yes, I see my psychologist because I've been sexually abused by my parents."

The need to be looked on as an ordinary human being was also present in relation to the diagnosis. The participants expressed a fear that some of the feelings they talked about might be seen as expressing mental illness, which could be interpreted in diagnostic terms and not just as ordinary human feelings. The diagnosis here mostly represented "bad" mirroring, which focused on inferiority and made it hard to feel autonomy and competence.

Sometimes you watch your tongue quite a lot ... so you avoid saying something that can be understood as mentally ill.

Consequently, an experience of being labeled mentally ill was present, which contributed to a feeling of being disregarded. Expressions of stigmatization were related to contacts both with psychiatric care and with others.

When I first started here, I thought they ran over me a bit. That you had a stamp on your forehead that you were mentally ill /.../ try to change the fact that it's so taboo to feel bad ... that it should be something to be ashamed of.

A recurring concern was that the staff, most often the psychiatrist, had the right to interpret what the truth was. Such a situation could occur when the

participants attempted to express their views on their treatment. Such trials could result in feelings of being perceived as a “sick person” and as someone incapable of conversation or listening.

Among the worst things I’ve been faced with was a psychiatrist who only told me to take medicine, that there was no point in going to a psychologist to talk. That there was nothing to do but to remove everything except medication.

In their role as patients, some participants chose not to express their opinions or were afraid that their wishes would be interpreted in a negative light. They feared being seen as uncooperative, which could result in negative consequences for future care.

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.

Comments which also were present during the focus groups were directed criticism, which could be a way of protecting oneself from being defined by someone else and of retaining power over one’s own perceptions.

When I meet people in the care, who tell me what to feel ... then the care isn’t very scientific; it’s more like a religion.

Relate to me. The importance of relationships and the wish to have someone to talk to and be with constituted a recurring theme. Furthermore, being in a psychosis evoked a need for structure and to be held by someone else, in order to tolerate and understand one’s surroundings. Consequently, seeing the same personnel on a regular basis and having the possibility of returning to the same place were aspects that resulted in feelings of security. If the staff assumed that role, this became an opportunity to gain trust in an unpredictable life.

Trust that she’s there; also, when I call ... she listens. I mean she’s there, she’s there even when I just call and ask if I can come and see her ... she says “sure” ... just those words, to say sure, that’s important to me.

However, psychiatric care was sometimes described as impersonal, as instrumentalistic with a focus on

efficiency. One participant compared institutional care to an assembly line.

It’s a bit like mass production, it’s a stamp. And after a look in the medical record ... yes, we change the medicine there, stamp and move on. Stamp and move on. I just hope I won’t get ill again.

Participants felt that staff lack of time was one of the most serious hindrances to their taking control over their own lives. This was most present in the participants’ experiences of institutional care. Discontinuity in relationships between patients and professionals, especially psychiatrists, was highlighted as an obstacle to interaction. When patients had to repeat their stories to new psychiatrists, this evoked feelings of anonymity and alienation.

But then I got another doctor. It didn’t feel good when I was supposed to share my story all over again. I felt that it was a huge failure.

Standing on one’s own

This theme reflects how participants formulated their experiences of gaining control over their lives. The main aspect was the transfer of power, which took place when participant competencies were acknowledged by the staff. A key issue here was being listened to and gaining knowledge and information. Furthermore, participants expressed a need for encouraging and supportive professionals.

Listen to me. When planning for the future, the need for relationships was also stressed, not in the same caretaking way as during acute psychosis, but more as a support function. The importance of being listening to was emphasized.

Anyhow, I felt that I was involved somehow ... they were very good ... had good contact with them, thought they listened to me, to my own thoughts about what I wanted to do, and they tried to encourage me to do it.

In various ways, the participants stressed the importance of being listened to, not least concerning medication.

And kind of listens to me when I say that I have side effects ... so of course, it’s important that it works.

Despite positive experiences of staff efforts, several stories described feelings of not being listened to or understood by the psychiatrist and difficulties

discussing and influencing medication issues. In many cases this was like “talking to a wall”.

I knew it was side effects caused by the medication. But I can't yell to his face “get rid of that medication!” Because then one will not be dealt with well. The only tool I had was to say that the medicine gave me suicidal thoughts. How do you tell someone that you're not being medicated appropriately. You must not be too much of an expert—you can't challenge the doctor.

Lack of relationships, discontinuity, and having nobody to talk to resulted in insecurity.

It was as if no one sat down and talked to me. And I missed that, someone grabbing me and sitting me down and talking to me and telling me about what was going to happen.

Guide me. Having knowledge of one's own problems was seen as a prerequisite for finding constructive strategies for handling life. However, when life became chaotic, it could be hard to trust one's own perceptions. The participants described their difficulties distinguishing between disease and reality, and they were also aware of their need for various forms of treatment. They cited experiences of therapy and medication that had made a difference, and mentioned staff members who had helped them “grab what's theirs,” in both life in general and in care.

I need medicine to feel well ... and that's why I need good contact with a doctor who understands that and understands what dose I should have, and so on ...

The participants sometimes experienced the psychiatric system as a strange and scary environment with its own rules and regulations. Mastering such a situation called for information, while a lack of knowledge and information resulted in feelings of passivity and alienation.

Got this feeling of that you were ... well, now you're gonna get passed into a system and then you'll be stuck there ... didn't know so much about this world ... need to know ... didn't have any experience of this before.

Being identified as a psychiatric patient resulted in feelings of stigmatization and an inability to meet society's normative expectations. Information and support were necessary to be able to handle being a patient and to find supportive individuals and contexts outside the psychiatric care system.

Once you get out of the hospital, you should receive support, a list of different places to go to, because you may not have the strength to look that up—I didn't! Perhaps they could suggest somewhere for me to go ... maybe even offer to help or join me there or ... you're not able to handle it by yourself.

When support and guidance were offered by somebody, that person was compared to a mentor making it possible to increase the individual's ability to manage everyday life.

... it takes time to learn and you need someone teaching you ... what ever it is. Takes time to learn whatever it is, and you need help. In the same way as you need a football instructor when learning to play soccer.

Face-to-face information about diagnoses and medical treatments was highlighted as crucial. Sometimes information about the participants' psychiatric diagnoses was delivered by post, which made things worse in an already difficult situation and led to feelings of neglect. The following participant was left alone, without guidance, to try to make sense of her diagnosis.

It was kind of shocking, I have to say ... it was probably the first medical certificate that I'd ever received. Paranoid schizophrenia it said, that I remember ... received it at home. Yes, I was completely shocked, and it's possible that it was correct ... to a certain extent ... but I felt that they could have talked about it before ... told me, informed me.

Give me hope for the future. After the more acute phase, certain activities were viewed as necessary for recovery and for not remaining in a passive role. If these activities were facilitated, the individual could find ways to believe that it was possible to handle what the future would bring; in the context of an ongoing trusting relationship, hope about the future could then emerge.

Have a plan for how to move on ... what kinds of activities you want to do and work training ... that's something I have to say that they've been pretty good at.

Activities could be seen as signposts pointing towards the future; they produced a sense that the trials undergone and attempts made were worthy and meaningful. With staff support, they could result in

feelings of safety and hope. Consequently, an absence of plans for the future resulted in uncertainty.

Well, there is no real “next step” right now /.../ there perhaps should be the possibility of getting into traineeships or work or whatever.

Individually tailored care and the possibility of choosing were other important aspects. When a professional acted more like a collaborator or partner than an expert, it became possible to gain hope for the future. The same thing happened when the individual’s own responsibility to achieve a better life was supported by the professionals. Receiving help in reflecting on and formulating individual needs and goals was thus experienced as helpful:

It’s very good here because they are very progressive in their way of thinking, and it’s not just that everyone should have the same sort of, what’s it called, care. They look at every person and I think that’s good ... they care about you, as a person, and you can tell this from when they receive you. They look after your needs and all the time they say, they say all the time, “Determine for yourself what you want. What do you want to do? Then we’ll do it.” That was really good.

Comprehensive understanding

During acute psychosis, participants experienced feelings of horror, making it hard to know what belonged to the inner versus the outer world. This situation could be even worse in the absence of relationships and information. However, if it was possible to relate to someone, this relationship became a lifeline, even offering a possibility of psychological survival. During the struggle to live a “normal” life, staff support emerged as a key refrain. Consequently, there was a need for staff to give their time, provide support through information, and mirror the capacity and hope that now belonged to the patient. It was also important for staff to listen and understand, so they could be aware of and respect patient viewpoints. The experience of rarely seeing the same psychiatrist was also a recurring theme, leading to situations in which patients had to retell their stories over and over again. Patients also found it confusing that different psychiatrists had different opinions about care and medication. Sometimes patients struggled to be “good patients,” for fear of being regarded as mentally ill and incapable of having their own opinions. However, even in narratives about stressful situations and feelings of being ignored, the patients tried to see

the professional’s viewpoints, as reflected in remarks such as “but maybe it’s their walls ... of course it must be hard to work as a doctor in a psychiatric infirmary.”

Discussion

The present study sought to improve our understanding of how a group of patients, who are often treated as invisible and whose voices are rarely heard, described their wishes and needs regarding the psychiatric care system.

Feelings of powerlessness, fear, and vulnerability often arise in people with severe mental illnesses (de Haan et al., 2002; Grubaugh et al., 2007), and such feelings were a recurring theme in the present study. Powerlessness was also manifested in disregard: patients were effectively rendered invisible when none of the psychiatric staff noticed their needs and predicaments. Periods of acute psychosis were experienced as confusing and chaotic. Participants cited examples of humiliation at the hands of staff, especially when they were inpatients. Another recurring theme was lack of information, which resulted in insecurity, loss of control, and feelings of powerlessness. This predicament was most notably present in relation to medication and choice of treatment, such as when one patient expressed a need for psychotherapy and the psychiatrist saw this as something counterproductive.

Several factors emerged as prerequisites for the patients’ feelings of trust. Relationships characterized by continuity, caretaking, and “holding” were associated with trust. It seemed important to have access to an environment that offered calmness and fulfilled basic needs. In other words, basic care could be understood as an important factor promoting feelings of trust. Trusting relationships and a safe and calm environment are also prerequisites for a secure base, which includes help with regulating stimulation from an overwhelming outside world, as well as to be mirrored in good relationships (Bouchard et al., 2008; Bowlby, 1994). Consequently, during acute psychoses, the staff served as parental figures, and having such a relationship with a staff member was a prerequisite for feeling safe.

Closely related to the feeling of trust was the feeling of hope, and to feel hope, the patient had to be listened to, understood, and accepted by professionals. Hopelessness emerged foremost when participants were inpatients; one participant even compared this kind of care to an assembly line. Professionals play an important role in giving patients hope, in some periods even supplying “vicarious hope” to their patients. Other important factors in gaining hope

include being encouraged to participate in daily activities to structure one's life, and being encouraged to plan for the future. Feelings of hope seem to be an important mediating factor in adjusting to and recovering from physical illness. The present results highlight the fact that trusting relationships are a prerequisite for gaining hope.

Like other studies, this study demonstrates that becoming a patient in the psychiatric care system is associated with stigmatization. Staff attitudes and behavior are important in this regard, as they can either confirm or reduce feelings of patient stigmatization (Verehaege & Bracke, 2007). Being reduced from a "whole and normal" person into a tainted, "bad" person was a recurring theme. This reduction took place in both psychiatric care institutions and everyday life. Participants told of having opinions differing from those of the psychiatrist, and described how such disparities resulted in a fear of being regarded simply as mentally ill or as non-cooperative. However, feelings of stigmatization were reduced when symptoms were explained and normalized. Another common experience was that staff often focused on the patients' deficits rather than their actual problems.

Narratives about staff helpfulness and support were common and were described as decisive for patients' ability to get on with their lives; with the support of such relationships and information, patients were able to gain hope for the future. There were various prerequisites for delegating power to patients in more "patient-driven" relationships, for example, when patients were treated as able and competent individuals worth listening to. This process extended to "bad periods," when power was transferred from the patient to the professional, who became a vicarious decision-maker. In this way, the professional was attributed the role of representative looking out for the best interests of the patient. During "better periods," the relationship was characterized by collaboration and "reciprocal power," and the professional was seen as a partner or facilitator embodying equality and power sharing.

Concluding remarks

It is possible that staff members focus more on life traumas that occurred before the individual turned to the psychiatric system for care instead of on traumas caused by the psychiatric system itself. The present results suggest it is crucial that staff ask about traumas caused by the psychiatric system. It should be possible for today's patients to discuss the traumatic experiences caused by the system itself, and work through them with staff.

Although the themes of the focus groups were not introduced in chronological order, during the analysis, it was easy to follow the process each participant had undergone. In the 15 different stories that emerged, the common denominator was the huge struggle patients experienced in trying to devise livable lives.

Participants described many experiences with staff, some that reflect a humanistic attitude on the part of staff, others that do not. The question not answered by this study is one that participants alluded to throughout the sessions: To what degree are all of us in society willing and able to acknowledge the competencies of individuals suffering from psychosis, and of holding positive views about them.

Acknowledgements

The study was granted by Vårdalinstitutet—the Swedish Institute for Health Sciences

Conflict of interest and funding

The authors have not received any funding or benefits from industry or elsewhere to conduct this study.

References

- Balint, M. (1972). *The doctor, his patient and the illness*. New York: International Universities Press.
- Barnes, D. (2000). Interprofessional education for community mental health: Attitudes to community care and professional stereotypes. *Social Work Education, 19*, 565–583.
- Bouchard, M.-A., Lecours, S., Tremblay, L.-M., Target, M., Fonagy, P., Schachter, A., et al. (2008). Mentalization in adult attachment narratives: Reflective functioning, mental states, and affect elaboration compared. *Psychoanalytic Psychology, 25*, 45–66.
- Bowlby, J. (1994). *En trygg bas [A secure base]*. Stockholm: Natur och Kultur.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77–101.
- Chee, C. Y. I., Ng, T. P., & Kua, E. H. (2005). Comparing the stigma of mental illness in a general hospital with a state mental hospital: A Singapore study. *Social Psychiatry and Psychiatric Epidemiology, 40*, 648–653.
- Corrigan, P. (2004). How stigma interferes with mental health care. *American Psychologist, 59*, 614–625.
- Corrigan, P. W., & Lundin, R.-K. (2001). *Don't call me nuts! Coping with the stigma of mental illness*. Tenley Park, IL: Recovery Press.
- de Haan, L., Peters, B., Dingemans, P., Wouters, L., & Linszen, D. (2002). Attitudes of patients toward the first psychotic episode and the start of treatment. *Schizophrenia Bulletin, 28*(3), 431–442.
- Eisen, S. V., Dickey, B., & Sederer, L. I. (2000). A self-report symptom and problem rating scale to increase inpatients involvement in treatment. *Psychiatric Services, 51*, 349–353.

- Ekeland, T.-J., & Bergem, R. (2006). The negotiation of identity among people with mental illness in rural communities. *Community Mental Health Journal, 42*, 225–232.
- Finfgeld, D. L. (2004). Empowerment of individuals with enduring mental health problems: Results from concept analyses and qualitative investigations. *Advances in Nursing Science, 27*, 44–52.
- Golberstein, E., Eisenberg, D., & Gollust, S. E. (2008). Perceived stigma and mental health care seeking. *Psychiatric Services, 59*, 392–399.
- Grubaugh, A. L., Frueh, B. C., Zinzow, H. M., Cusack, K. J., & Wells, C. (2007). Patients' perceptions of care and safety within psychiatric settings. *Psychological Services, 4*(3), 193–201.
- Hansson, L., & Björkman, T. (2005). Empowerment in people with a mental illness: Reliability and validity of the Swedish version of an empowerment scale. *Scandinavian Journal of Caring Sciences, 19*, 32–38.
- Liggins, J., & Hatcher, S. (2005). Stigma toward the mental ill in the general hospital: A qualitative study. *General Hospital Psychiatry, 27*, 359–364.
- Linhorst, D. M., Hamilton, G., Young, E., & Eckert, A. (2002). Opportunities and barriers to empowering people with severe mental illness through participation in treatment planning. *Social Work, 47*, 425–434.
- Morgan, D. (1998). *The focus group guidebook*. Thousand Oaks, CA: Sage.
- Puchta, C., & Potter, J. (2004). *Focus group practice*. London: Sage.
- Rogers, T. S., & Kashmina, Y. (1998). Nurses' responses to people with schizophrenia. *Journal of Advanced Nursing, 27*, 195–203.
- Sadow, D., & Ryder, M. (2008). Reducing stigmatizing attitudes held by future health professionals: The person is the message. *Psychological Services, 5*, 362–372.
- Servais, L., & Saunders, S. M. (2007). Clinical psychologists' perceptions of persons with mental illness. *Professional Psychology: Research and Practice, 38*, 214–219.
- Segal, S. P., Hodges, J. Q., & Hardiman, E. R. (2002). Factors in decisions to seek help from self-help and co-located community mental health agencies. *American Journal of Orthopsychiatry, 72*(2), 241–249.
- Slade, M., Leese, M., Taylor, R., & Thorncraft, G. (1999). The association between needs and quality of life in an epidemiologically representative sample of people with psychosis. *Acta Psychiatrica Scandinavica, 100*, 149–147.
- Verehaege, M., & Bracke, P. (2007). Organizational and individual level of determinants of stigmatization in mental health services. *Community Mental Health Journal, 43*, 375–399.
- Vogel, L., Wade, N. G., & Haake, S. (2006). Measuring the self-stigma associated with seeking psychological help. *Journal of Counseling Psychology, 53*, 325–337.