Research Article

The Knowledge Concealed in Users' Narratives, Valuing Clients' Experiences as Coherent Knowledge in Their Own Right

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Objective. As the history of psychiatry has been written, users have told their stories and often presented pictures incompatible with the professional or official versions. We ask if such a gap still exists and what the ethical as well as epistemological implications may be. *Study Design*. The design is based on a hermeneutic-phenomenological approach, with a qualitative content analysis of the narratives. *Data Sources*. The paper draws on user narratives written after the year 2000, describing positive and negative experiences with the mental health services. *Extraction Methods*. Among 972 users answering a questionnaire, 492 also answered the open questions and wrote one or two stories. We received 715 stories. 610 contained enough information to be included in this narrative analysis. *Principal Findings*. The stories are coherent, containing traditional narrative plots, but reports about miscommunication, rejection, lack of responsiveness, and humiliation are numerous. *Conclusions*. The picture drawn from this material has ethical as well as epistemological implications and motivates reflections upon theoretical and practical consequences when users' experiences do not influence professional knowledge to a larger degree.

1. Introduction

The stories from a subjective or patient perspective have followed the official story of psychiatry like a side stream [1–3]. Listening to the nonexperts, "ordinary people" or "victims of history" [4], has a long tradition in social science. Women, workers, the colonialized, religious minorities, prisoners, the ill, and also the "mad" have in turn had their voices heard. But listening to valuing and appreciating the stories of the mentally disabled has been a more complicated case and has needed more time for reasons we will return to. As expressed by Molinari [5] there has been a kind of an unequal relationship between the client who writes to express his/her truth and the professional reader who reads the story to confirm his/her diagnosis.

Even if users' perspective gradually has been set on the agenda and user involvement is established as a method for improving the health services [6–8], user involvement in the field of mental health care still does not avoid the asymmetrical relations between users and professionals, not the least because of the possibility of diagnosing users' opinions [9]

rather than receiving their feedback and narratives as helpful corrections necessary in the process of improving the delivery of health services. As a consequence user involvement may be regarded only as an empowerment strategy for users and not a method by which professionals may also achieve new insights [10]. Then, necessary changes in the health services aiming at mutual collaboration may be neglected. Barker [11] holds that it is not the professionals who empower the patient; it is the person with mental illness who is in position to empower the professional. The only way to be of real service is to learn from the person. Having learned what to do for the patient, from him/her, the professionals can gain some understanding or insights, which changes them, however imperceptibly. This change in professional attitude influences the next interactions and so on (page 321).

2. The Aim of the Study

The study aims to analyse clients' stories written after the year 2000 and reflect upon the message in the stories as well as how

clients experience that their stories are received and used in the process of improving the health services. Further, clients' variegated experiences and the need to communicate those experiences to leaders and professional experts are discussed from ethical and epistemological perspectives.

3. Methodology

The paper refers to a data material consisting of 492 users' narratives about meetings with the mental health service system [12]. The narratives were written in response to two open questions at the end of a comprehensive questionnaire: (1) Would you like to tell a story from a special meeting with a helper or a health service system that represented a turning point in your life? and (2) If you have had strong negative experiences, would you like to describe such an event?

Our methodology is anchored in a hermeneutic-phenomenological tradition, focusing on individuals' subjective experiences and interpretations, where credibility depends on the coherence in the argument [13, 14]. Further, we use elements from narrative methods in order to shed light on common narrative plots, power relations, and the implications of speaking from a nonhegemonic position [15].

Narratives can be defined in different ways, but in this paper we use the much employed definitions of Hydén [16], Edwards [17], and Mishler [18] who define narratives as stories written in a coherent way, aiming at explaining and making sense of events, legitimating actions and reactions, confirming identity, and adding meaning to experiences. Mishler [18] also maintains that the presentation and confirmation of identity is a constant factor in all personal narratives and is related to the creation of meaning. The construction of plots, understood as phrases describing a cause, an effect, and a link between them, informs the kind of meaning that is added to the experience and how cause, effect, and meaning are perceived [19].

4. Respondents

The data we refer to was selected from a larger study carried out in cooperation with the national user organization, Mental Health Norway (MHN). MHN was chosen because it is the largest user organization. The organization has a reasonable well-functioning relationship with the government; for example, MHN regularly serves as a consultative body and an administrative system which could assist in the collection of data. During the period of data collection, there were about 5000 members spread over the whole country. About 4000 of them, chosen randomly, were invited to take part in the study. Nearly 1/4 responded. The user organization Mental Health Norway could not provide any information about the profile of their member group (like age, gender, occupation, social security support, or experiences with the help service system), but the spread we found regarding the mentioned indicators tells that the experiences are applicable for several groups of people. 492 of the respondents (151 men and 341 women, aged 19–90 years) also answered one or both of the two open questions at the end of the questionnaire. 223 of

the respondents reported both a positive and a negative story, while 112 wrote only a negative story and 157 wrote only a positive story. In total we got 715 stories, some with a lot of information and others with not enough information to have them categorised in any way. The latter stories were excluded from the analysis and consequently 610 stories remained for the categorisation process. The respondents who were included in the categorisation process have experiences from all parts of the mental health care system, traditional psychiatric institutions, outpatient clinics, day centres, and individual therapy. 67% received disability pension, 13% had a job, and 20% combined disability pension with a job or studies.

The narratives were analysed by qualitative content analysis [20]. The stories were read through several times in order to discover themes embedded in the texts and to obtain a sense of the whole. Manifest content in the texts is presented as categories that may also be seen as expressions of the latent content. The presentation of meaning units in categories is based on the researcher's judgment and validated in a process where the researchers proposed categorization independently of each other.

5. The Narratives

In the following we present an overview of themes emerging from the stories and thereafter some example stories, chosen from all the four main categories as shown in Table 1 and which also illustrate two overriding narrative plots: the search for meaning and the confirmation of identity. Recognizing clients' stories as coherent and valuable knowledge is then discussed from ethical and epistemological perspectives.

When studying the therapeutic framework described in the stories we found—as shown in the table—two main themes: a mainly psychiatric medical approach and a humanistic-existential psychosocial approach [21]. Under each theme there were two main categories: (1) the help service experienced as being beneficial and (2) negative experiences related to rejection, humiliation, or threats. The majority of positive experiences were found where a humanistic-existential psychosocial approach was dominating and the majority of negative experiences were found in a medical context where diagnoses and medicines were the dominating means by which the clients were met.

5.1. The Creation of Meaning as a Narrative Feature. From a humanistic perspective the meaning dimension is essential to human beings [19, 22, 23]. By telling our stories we can create meaning by establishing a culture-specific sense of order, which makes life worth living [24–26]. The following stories illustrate how the mental health clients' stories display deeply human traits and deserve status as coherent knowledge in their own right and how the experience of meaning is related to (a) regaining a feeling of worth and dignity, (b) realizing that hardships can give insights and increased ability to understand and help other people, (c) discovering connections between earlier assaults and depression or anxiety, and (d) putting life experiences together in a story which can be imparted and contribute to the richness of life stories.

TABLE 1: A summary of all the narrative themes under four main categories.

Psychiatric medical approach	Humanistic-existential psychosocial approach
Medical-instrumental help experienced as beneficial ($n = 18$)	Positive experiences with psychosocial and social help and support ($n = 297$)
Beneficial medication practice	Traumas worked through
Medicines and following up	Working through traumas
Medicines that functioned ok	Obtained selfinsight
Helped to reduce medicines	A new start and quality of life
Diagnosis experienced as a relief	Experienced community
Enough time for diagnosis	Trust, confidence, and feeling of worth
Diagnosis and following up	Spiritual experiences
The experience that service is available	Peer support and network
Access to hospital	Welfare/socio-economic help
Hospital as a place of refuge in crisis	Practical help
	Housing and activities
Psychiatric-medical help experienced as threatening and humiliating ($n = 225$)	Rejection and encroachment in therapeutic relations with a humanistic-existential psychosocial approach ($n = 70$)
Experienced rejection and isolation in treatment context	
Not taken seriously	Bad communication
Rejection, lack of treatment	Miscommunication
Just stored away, no following up	No understanding
Strain caused by treatment	Client's dilemma rejected
Medicines abruptly removed	Childhood/trauma rejected
Negative side effects of medicines	Persuasion to divorce
Wrong diagnosis	Children not cared about when parents were sent to hospital/received help
Disrespect and threat to integrity	Unethical behavior from the therapist
Compulsion, punishment	Inappropriate behavior from the therapist
Treated violently	Appointments not respected
Accusations, infringements	

I had taken an overdose of medicines and was an in-patient at a local hospital. I made very good contact with a nurse there. She sat down at my bedside and talked to me. Gave me a good lotion after I had cut my arms with a broken piece of mirror and gave me the whole tube and a hug when I was sent to the psychiatric ward. I will never forget her! Woman, age 31.

To me the organisation MHN (Mental Health Norway) meant more than "the good helpers" I met in hospital 1.5 years ago. To experience fellowship and the feeling that you are doing something useful for others means quite a lot. Woman, age 45.

In the hospital I took part in body-oriented therapy. Then I got into contact with forgotten experiences from my childhood, experiences that my body remembered. It was a very painful experience and I needed years to heal the wounds. But this experience was a breakthrough in the effort to recover, and many questions were answered. Woman, age 54.

The narratives contain several plots describing relations between being labelled as a psychiatric patient and various kinds of rejections. The meaning dimension appeared when the clients were given the opportunity to present their own coherent stories about what had happened:

The chief physician wanted to give me 16 mg Trilafon. My experience told me that I then would be totally unable to think. 8 mg was enough to get me on my feet again. Then I was medicated by force, held by 4-5 persons while I got an injection in my buttocks. Gradually they discovered that I did not resist. Because I was also sexually abused as a child this was a horrible experience that still causes me to shiver as I write it down. It was good to have the opportunity to write about it. Man, aged 50.

5.2. The Confirmation of Identity. Narrative properties like efforts to confirm or protect identity and also to give rational reasons for the way of acting are clearly projecting in this material, but in addition some extra dimensions related to the confirmation of identity were discovered; the expressions of disempowerment and the unusual strong efforts to confirm identity and justify oneself as a rational being are as follows.

I was afraid and thought someone would kill me. I was prevented from talking to the doctor and locked myself into the bathroom. The water warmed and comforted me. They came in. I said: Do not touch me; I will go to my room. They did touch me. I got angry. I am sad I did not write this when I was angry and felt I was not listened to. I bit the woman who touch me and tore up her blouse. She got angry and wouldn't let me talk. I was awake the whole night because of anxiety. She reported how hopeless I was. I think she should have listened to me; maybe we could have avoided the episode in the bathroom if she had called the doctor. I did not trust her, that's the reason I could not tell her anything. When I locked the door to the bathroom I can understand that they maybe were worried about me, but it was not necessary to touch me, because I would have gone myself and, furthermore, I was in a humiliating situation there in the bathtub. I did pay for the blouse. Woman, age 62.

Most of the negative stories are reports about the lack of responsiveness, which invoke feelings of rejection as well as humiliation. Besides they illustrate that feedback from clients is neither necessarily welcomed nor used to improve the quality of the services.

To be taken care of, listened to, respected, and supported means that pain and suffering is made bearable and several informants reported that relations marked by these qualities helped them back to a normal life and even to a richer life than before.

For 13 years I had the help line number for the anxiety self-help organisation on my bulletin board. I did not dare to call. But then I decided that I had to. I called. After the talk I dared to visit them. When meeting the leader I for the first time experienced not to be alone with my bottomless shame. Other people had the same experiences. This happened one year ago and today I feel that life is opening up. Woman, age 44.

The need to confirm or reestablish identity seems to be of special importance when a client's dignity has been threatened or lost due to a humiliating process in the course of treatment. The disempowered client language and the efforts several informants spend on confirming identity emerge as the most interesting discoveries when looking for narrative plots in the clients' stories. An underlying message is about the need to reclaim dignity, which in turn means integration of the experience of lost honour [27, 28]. Reshaping identity may involve a new kind of honesty meaning that there is no reason to pretend, thus being willing to reveal what has threatened the self-image and sense of dignity. A main question concerns the health service system's ability to understand the processes that represent a threat to the person's integrity and the implications of lost dignity.

It is a paradox that the experience of lost honour is often related to being a client in the health service system. Important information about the social order is embedded in this paradox. Stories about compassionate encounters marked by responsiveness, genuine care, and empathetic understanding do not have the same need of strong legitimating explanations.

After having fought with all kinds of bureaucracy and systems I at last considered committing suicide as a final escape. In desperation and by accident I passed a house where Catholic monks lived. I am not a Catholic, but was met with incredible

warmth and not least, respect. The brother invited me inside and we talked until I felt able to walk home. Later we had several talks about thoughts I was struggling with. The brother's genuine wish to help showed through and he offered to engage himself also beyond the conversations. Until this day I have never met a person with an equivalent capacity to look into the soul and meet another person on this person's premise. I could also contact him whenever I wanted. This caused me to restrain myself, but I still experienced the feeling of security. Man, age 43.

The stories have illustrated the search for meaning as well as efforts to confirm identity. The composition of plots is an overall demonstration about rationally described connections between the users' earlier or recent experiences and their present situation and exemplifies the strong need of experiencing meaning and confirming identity. At the same time they inform on personal experiences and knowledge which can benefit the health service system if listened to and taken seriously.

The efforts to demonstrate rationality appeared as extra strong when the users described situations where their identity and honour were threatened. Very detailed descriptions about what happened and why tell about feelings of powerlessness or that understanding cannot be taken for granted. Situations of powerlessness and threatened identity also informed about a distance gap experienced between the way services were delivered and what the users themselves regarded as beneficial.

6. Ethical Reasons for Recognising Clients' Stories as Coherent Knowledge

Ethics concerns protecting dignity and respecting integrity and represents fundamental values in human relations. In research, these ethical principles should always be considered. Schaanning [29] has suggested that in a situation where we can no longer relate to a final truth as being the "last instance" ethics should take on the role of being this "last instance." Research will then be evaluated by its ability to facilitate the implementation of actions to the good, improve human conditions and preserve dignity, and empower patients to exercise increased control over their lives [30–32]. But in the field of mental health care ethical guidelines can also contribute to the silencing of clients' voices, as protection barriers are set up against discussing personal subjects with "vulnerable" persons [33]. This emerges as a paradox as there are no indications that mental health clients themselves want this special protection. In fact, being able to relate their tales of suffering could be a way for the person to find an opening to their inner worlds and interpretations of what has been experienced and thus serve an essential path towards its alleviation (cf. [34]). The mentioned ethical guidelines stem from a paternalistic attitude saying that vulnerability in this field may be related to lack of self-insight or ability to handle one's own emotions. So, ethical guidelines by themselves do not necessarily protect clients' interests, which further points to the importance of upholding clients' right to tell their stories and making dialogic communication a main ethical

concern [35–37]. As underlined by Bachtin [38] dialogic communication is the essential realm of humans and "to deny the dialogue is to deny the human being" ([38]: 282).

Users' perspectives and users' choices have been on the agenda for some decades, but there have been unsaid reservations, as highlighted by Morrison et al. [39], asking, antipsychotics, is it time to introduce patient choice? As mental health services have for decades been dominated by the psychopharmacological "revolution," stigmatisation, and lack of response to clients' expressed needs can hardly be understood without observing the tradition which allows professionals to medicate clients without their free and informed consent [40]. To Barker and Buchanan-Barker [41] this concerns the major ethical dilemma, that is, autonomy versus paternalism in the field of mental health. They criticise the ethical literature for avoiding dilemmas raised by the use of coercion, for contributing to the confusion over the nature of "mental disorder," and for embracing the misplaced paternalism they see as part of the medical tradition. If there is a single psychiatric "truth" they say, "it is that people had a better chance of recovery from a psychiatric 'breakdown' *before* the advent of psychiatric drugs 60 years ago, than they do today" ([41]: 455, see also [42]). Given this knowledge the use of coercion as well as a nonresponsive attitude in general raises serious ethical questions concerning autonomy and lack of reciprocity in therapeutic settings. A disputable scientific fundament is not, according to human rights' legislation [43], able to justify the serious encroachments into peoples' lives we talk about here. The convention on the rights of people with disabilities [44] then takes further steps to transform mental health users' status according to ethical standards, by among others underlining legal capacity as a universal property (art 12) and the universal right to healthcare including being on the basis of free and informed consent (art 25). Ethical reasons then also have become legal reasons, which will support the process of implementing ethical standards related to the recognition of clients' voices.

7. Epistemological Tensions in the Field of Mental Health Care

Users' own stories have challenged the history of psychiatry and also become assimilated into it so that tensions between users' and professionals' understandings are partly transformed into tensions between two different professional and epistemological approaches where roughly spoken the first one sees the evolution of psychiatry as associated with progress made in biomedicine while the other contributes by reflecting about context and how society influences the development of mental illness and how we perceive it [3]. The division may be traced back to different sources. By the writings of Foucault [45], Scheff [46], and Goffman [47] the ideological aspects behind all historical analyses became visible and also the relations between broader social trends like social disciplining, regulations, division of labour, definitions of deviation, and stigma processes on one hand and how we define and handle mental disabilities on the other hand. In philosophy and psychology a new concept of

Self originated as studies into rationality and consciousness revealed human beings as less rational and with a less stable Self than presumed earlier [29, 48]. This new concept of Self also contributed to changed attitudes about madness and influenced treatment institutions. Both critical approaches advocating contextual understanding and new insights into human beings' limited rationality seem to have strengthened the arguments for listening to the "voices from below" and confirmed patients' right to possess their own clinical experience [3].

Along with controversies over the rationality of human beings in general, the dispute between professional approaches concerning mental patients' lack of self-insight still goes on. Even if attempts at defining the insight phenomenon are scarce [49, 50], information about the opinions and experiences of mental health clients is lost to a greater degree compared to information obtained from other groups of clients, which may be explained by the fact that the voice of the client is often seen as less valid because he/she is receiving mental health care [51].

In the postpsychiatry movement, it seems like clients' perspectives emerge as a critical element without denying traditional psychiatry as a science [52]. Maybe this movement can bridge the gap between the two approaches. But looking at the different ways psychoses are understood: as from outside, as biological defects which can be objectified, independent of the individual, or as a phenomenon anchored in fundamental human conditions and something that should be understood from inside, in the light of the subject's own experiences [53, 54], the bridge is not easily discovered.

Psychoses seen as pure irrationality sustain the impression that mental health clients lack self-insight to a larger degree than other groups of clients. In order to have clients' experiences accepted as coherent knowledge in their own right, it seems important to accept the need of reciprocity and trust that the dialogue can be reestablished also in situations of confusion and seemingly irrationality.

8. Conclusion

The clients' narratives emerge as coherent and with obvious plots and are also often marked by less typical characteristics like the very strong efforts to confirm identity and demonstrate rationality and sometimes a kind of honesty or self-exposure which can best be understood in relation to a need of integrating the experience of lost honour. The common factor is the need to, and the importance of, being recognized as a subject. Several narratives—by illustrating the lack of responsiveness—repeatedly demonstrate the existence of a gap between users' and professionals' discourses. A main reason seems to be a hegemonic, professional discourse creating distance to users' own experiences and counteracting equal dialogues. Users' voices are still to a large degree silenced by an objectifying epistemology. Thereby the health services are also deprived of information that would be essential for planning, management, and further improvements in the field of mental health care.

Ethical Approval

The project was registered at the Norwegian Social Science Database (NSD) which has delegated authority from the Data Inspectorate of Norway to accept investigations in which sensitive, personal information is involved. The collecting of data organised in such a way that the researchers were unable to identify the informants. In practice the user organisation had ownership of the investigation and asked its own members to participate.
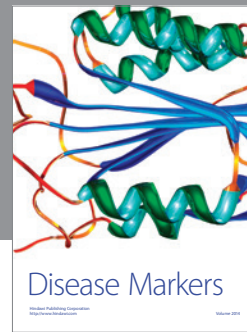
Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

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