

ORIGINAL RESEARCH

Experiences of the psychiatric specialist health services – The perspective of relatives of inpatients with severe depression

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Abstract

The aim of this study was to describe experiences of encountering the psychiatric specialist health services as a relative of an inpatient with severe depression. A qualitative and descriptive design using a phenomenographic approach was chosen. Twenty-four adult relatives, representing different ages, sex, level of education and relationship, were individually interviewed. Approval was given by the Regional Committee for Medical and Health Research Ethics, Norway (South East). Three descriptive categories emerged: Being in need of help, Being a resource and a participant and Being confident with the health care, with two conceptions each constituting the relatives' experiences of the psychiatric specialist health services. When relatives perceive that their next of kin is more severely depressed than the health professionals indicate, they describe it as a battle to obtain help. Relatives have knowledge of – and experience with the depressed person, and wish to share this with the staff. The relatives describe uncertainty as to whether the patient received high-quality care due to varying competence levels among mental health personnel. In conclusion, relatives' experiences and knowledge about the depressed person were not acknowledged as a matter of course. Thus, psychiatric specialist health services must take relatives' knowledge into account and initiate collaboration and support.

Key Words: Experiences, Inpatients, Phenomenography, Psychiatric specialist health service, Relatives, Severe depression

1 Introduction

Moving from institutional- to community- based care over the last few decades has led to an increased number of outpatient consultations in Norway, in addition to a decrease in the number of inpatient stays during the same period.^[1] Mental health services' dependency on support from families or other informal caregivers to take care of the next of kin has been reported as a result of deinstitutionalization. The families rather than the mental health service have become the major provider of care to persons with serious and

persistent mental illness.^[2] Collaboration between relatives and the mental health services is important, for the sake of the patient as well as for the relatives themselves,^[3,4] contributing to the relatives' satisfaction with the services and easing their burden.^[5]

Depression is one of the 10 global diseases entailing the greatest loss of life quality and years of life,^[6,7] and is estimated to affect 350 million people all over the world.^[8] Depression can be a severe and life-threatening disease, and the number of patients with recurrent severe depression re-

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quiring treatment in hospital wards is found to be high.^[9-11] In Norway persons with affective disorders constitute the largest number of patients treated in Psychiatric Specialist Health Services (PSHS) for adults within hospitals.^[12] Furthermore severe depression is reported to be the primary risk factor for suicide^[13] and may be considered as a challenge for the relatives.^[14]

Everyday life to the relatives of persons with depression is experienced as being highly affected by both objective and subjective burdens,^[15] and they are in danger of developing their own health problems.^[11,14,16-19] Relatives of persons with depression are in need for support for their own sake.^[19] Their situation become particularly difficult when they experience not to be taken seriously and included by the mental health care professionals.^[16,20,21] The main focus has been experiences of living with a person with depression and not primarily on the relatives' experiences of the mental health care service. Furthermore, the relatives have been recruited via outpatient clinics or support groups,^[16,21] after the patient is discharged^[20] and in some studies the depression diagnosis is not clearly defined.^[16,19,21]

Being a relative of a person hospitalised with a severe depression may be demanding for the relatives. To the best of our knowledge, there are no qualitative studies of relatives of inpatients with severe depression focusing on relatives' experiences of the PSHS. Hence, it is of interest to know how those relatives experience their contact with mental health professionals when their next of kin is cared for in a psychiatric ward. The aim of this study was to describe experiences of encountering the psychiatric specialist health services as a relative of an inpatient suffering from severe depression.

2 Method

The study employed a qualitative descriptive design using a phenomenographic approach. Ontologically the focus in phenomenography is on human experience, meaning that the only world we can communicate is the world that we experience, described as non-dualistic. The most essential feature of phenomenography is the attempts to describe the various ways a phenomenon can be experienced, which is known as the "second-order perspective", distinguished from what a phenomenon is, and which we can observe from outside, known as the "first-order perspective". Epistemologically it is assumed that a phenomenon can only be experienced in a limited number of qualitatively different ways.^[22,23]

In phenomenography, the terms experience, conceptualize, understand, perceive and apprehend are used synonymously.^[22,23] In the findings the descriptions of the phenomenon are on a collective level, showing the logical relationship between descriptive categories and the conceptions. The phenomenon in this study was the relatives' expe-

riences with the psychiatric specialist health services.

2.1 Settings and participants

Nine psychiatric wards in one hospital trust in Norway were included in this study. In Norway, an admission to the PSHS requires that a general practitioner (GP) located in the municipality assess the severity of the patient's depression before a referral can be done. One health professional from each unit was responsible for the recruitment.

From June 2010 to May 2011, inpatients were asked, both verbally and in writing, for permission to ask the person regarded as their closest relative to participate in the study. The inclusion criteria for inpatients were persons admitted with: a depressive episode (*F* 32.0-32.9) or a recurrent depressive disorder (*F* 33.0-33.9) according to the ICD-10 criteria,^[24] aged 18 years and older, and being assessed as having the capacity to give informed consent. The mental health personnel at the ward who knew the patient best were responsible to assess the patient's capacity to give informed consent. The exclusion criteria for inpatients were: persons with personality and behavioural disorders, bipolar disorders, substance abuse and serious somatic illness and psychotic disorders, with the exception of psychotic depression. A total of 70 inpatients fulfilled the inclusion criteria and 52 gave their informed consent.

Fifty-two relatives being the person the patient regarded as his/her closest relative were asked both verbally and in writing about participation. The inclusion criteria for relatives were: aged 18 years and older, and being able to read and understand Norwegian. Twenty-four relatives agreed to participate in the interview study and gave their informed consent in writing. The participants consisted of 16 females and eight males between the ages of 21 to 86, and included six spouses or cohabitants, two parents, two siblings and 12 children, while two participants had "other relationships". Two participants had a lower secondary school education, 14 had an upper secondary school education and eight had a higher education.

2.2 Data collection

Individual interviews were carried out and started by clarifying the aim of the study. The question asked was: "Please tell me about your experiences when encountering the PSHS as a relative of a person hospitalized with depression." Follow-up questions were also posed to probe more deeply into a given theme. Each interview lasted between 36-87 minutes, with an average length of 53 minutes. The interview contained two foci; in this study, the focus was on "relatives' experiences of encountering the PSHS", while the other focus was on "experiences of everyday life as a relative of a person diagnosed with depression", which is reported elsewhere.^[14] The interviews were tape recorded and transcribed verbatim soon after the interview by the first author.

2.3 Data analysis

The analysis moved from an individual to a collective awareness^[22] as a “pool of meaning”, and was performed in seven steps:^[25]

- (1) *Familiarization* - Each interview was read through several times to acquire an overall impression and to become familiar with the material.
- (2) *Condensation* - Statements corresponding with the aim of the study were identified. These statements were used throughout the analysis and inserted into tables, with a clear indication to the respondent from whom the statement originated.
- (3) *Comparison* - A preliminary analysis of each relative’s predominant way of understanding the phenomenon was made, and then the similarities and differences within the statements from all the participants were identified.
- (4) *Grouping* - Statements were grouped into concepts based on similarities and differences. These concepts were then compared in order to ensure that each of them had a unique character and the same level of description.
- (5) *Articulating* - Attempts were made to describe the essence of the similarities and variations within each group of conceptions, as well as looking for non-dominant ways of understanding the variation in the phenomenon.
- (6) *Labelling* - Suitable linguistic expressions for the various conceptions were denoted by constructing descriptive categories that best represented the findings.
- (7) *Contrasting* - Descriptive categories and conceptions were compared with regard to similarities and differences to ensure that they did not overlap.

Steps 3-5 were repeated several times until analytic closure was reached and no new conceptions emerged.^[25]

2.4 Ethical approval

The Regional Committee for Medical and Health Research Ethics, Norway (South East) gave its approval (ref. 2010/126). Ethical considerations were made regarding the integrity, confidentiality and voluntariness of the participants.^[26]

3 Findings

Three descriptive categories emerged, each consisting of two conceptions constituting the relatives’ experiences (see Table 1).

3.1 Being in need of help

This descriptive category shows that relatives, the depressed person and health professionals often perceived the depressed person’s need for help differently. Getting help when relatives deemed it necessary was described as being difficult.

3.1.1 Severity of the depression

The relatives notice that the depressed person is getting worse, but he/she may have difficulty assessing the situation: “I went to the doctor with her; she wasn’t able to express her own distress” (daughter). During admission and discharge, relatives describe feeling uncertain about whether the staff grasp how severe the depression is, and are uncertain as to whether he/she is well enough to be at home: “Well, well, she’s no better now on discharge than she was when she was admitted four weeks ago...” (husband). When relatives perceive that their next of kin is more depressed than the health professionals indicate, they describe it as a battle to obtain help. It is regarded as positive that health personnel take the time to get to know the patient and his/her history, *e.g.* when the GP makes a home visit to assess the patient before making a referral.

3.1.2 Access to help

Getting expert help when relatives experience the situation as being serious is a relief, although some find that this is a struggle and that the situation must be acute before help is given. Moreover, relatives may be uncertain who or where to ask for help: “I knew nothing about the system, and it was probably sheer luck that she was admitted” (son). Some did not have contact with or get help from the psychiatric specialist service until the next of kin had been hospitalized in a somatic ward after a suicide attempt. When depression recurs, obtaining help may take time even though the patient is known in the system from previous admissions: “It shouldn’t be so difficult to be admitted to a psychiatric ward. It’s the same old story every spring...” (husband).

Table 1: Experiences of the psychiatric specialist health services – from the perspectives of relatives of inpatients with severe depression

Descriptive categories	Being in need of help	Being a resource and a participant	Being confident with the health care
Conceptions	Severity of the depression	To share experiences	To rely on the staff
	Access to help	To be invited	To rely on the service

3.2 Being a resource and a participant

This descriptive category shows that relatives have knowledge of – and experience with the depressed person, and wish to share this with the staff. They also want to be met with responsiveness and be informed.

3.2.1 To share experiences

Relatives find it positive when the staff asks how they perceive the situation on admission, and furthermore when their experiences are seen important in the assessment of the patient's condition and treatment. One mother expressed this experience: "The psychiatrist didn't want to talk to us, just to our daughter." Others had taken the initiative themselves to inform the staff about what they considered crucial for both the treatment and follow-up. A daughter gave her input about the possible adverse effects: "I said that changes in her medication had maybe triggered the deterioration I was made to feel that this was something I knew nothing about, and of course I didn't."

3.2.2 To be invited

Relatives appreciate being acknowledged when they visit the ward. Although they are encouraged to get in touch when necessary if they had any questions, they fear being regarded as tiresome. Even if many questions surfacing during the hospital stay, many find it difficult to know what to ask about. Some relatives experience that mental health personnel put the duty of confidentiality first, thereby hindering the relatives from getting information and being involved in the treatment. Even though some relatives describe that the patient wants to involve them in the care, one mother wonders about this: "He's of age, maybe it would be different if he was under 18, maybe we'd have been more involved then?" Another mother had a different experience: "We've been included in discussions and involved as much as our son has wanted us to, and received information when we've needed it."

3.3 Being confident with the health-care

This descriptive category deals with relatives' confidence that the patient is receiving good treatment, that the staff is ensuring continuity in the follow-up, and that there also is continuity in the service through cooperation between the different trajectories of care.

3.3.1 To rely on the staff

Relatives express concern that the follow-up in the ward is inadequate, and that there were some differences between wards. A son said: "She was completely distressed and just wanted to leave the place, I said that there must be stricter surveillance on this open ward. I did not get the feeling that they were as alert as they were on the acute ward." Some even fear that the depressed person might commit suicide,

but they feel more secure when they experience that health personnel are accessible and observe changes in the patient. When relatives do not experience the expected improvement, they question the staff's competence: "I understood that this wasn't a place where she could get better. They couldn't take care of a patient who was so ill" (son).

The relatives' conception of continuity varied, and lack of continuity could be regarded as a challenge. Meeting one nurse who knows the patient, and who follows him/her throughout the course of treatment, is vital to them: "Her nurse was very proficient. The doctors changed, but we met the same nurse many times" (sister). However, some experienced this differently: "Because it was summer, there were a number of temporary staff and many different people to relate to, and the doctor was away for six weeks when dad was admitted. . . ." (daughter).

3.3.2 To rely on the service

Relatives find it reassuring when the discharge is well planned, with a smooth flow of information between the various treating institutions, e.g. in the transfer from the hospital to the municipality or between different wards at the same institution. For patients who need follow-up after discharge, information must be passed on to the next therapist so the relatives can avoid having to repeat this: "When she was transferred, I was asked exactly the same things. . . ." (daughter). When relatives have to relate to several wards, they have a basis for comparison. "Every time I came to visit, the contact person spoke to us together. She talked far more with me than they did in the other ward. . . ." (wife). Some relatives felt that the period of hospitalization was too short, that the treatment had not been completed, and that the patient was not well enough to be discharged – all of which put a great burden on relatives: "We said she couldn't just be discharged; she wasn't capable of managing herself, but in fact that's what they intended to do!" (daughter).

Others find that the discharges were well prepared: "There was a smooth transition. They took her home when she had leave from the hospital, and stayed with her to observe how she got along in the flat" (daughter).

4 Discussion

This study describes experiences of encountering the psychiatric specialist health services as a relative of an inpatient with severe depression. Between the onset of depression and hospitalization there may be a large span of time, and the relatives has taken much responsibility for their next of kin. Getting expert help when relatives experience the situation as serious is a relief, although some find that this is a struggle and that the situation must be acute before help is given. When there has been plans of suicide or a suicide attempt hospitalization is inevitable, which is dramatic not only for the depressed person, but also the relatives. A find-

ing in the present study was that some relative even feared that the depressed person might commit suicide during their hospital stay. The relatives were not confident about the care provided, and could not rely on the staffs' competence. One reason for this may be that they perceived the person's depression to be more serious than the health professionals. The relatives often know the depressed person very well and have noticed the development of the depression. Even if the person is known to the system, there is no guarantee of quickly finding help. Hansen & Buus^[20] reported that cohabitant relatives of depressed persons often felt marginalized in their attempt at drawing the attention of health professionals to the fact that their relative was having a serious depression and in need of hospitalization. There may be a hindrance in questioning the changes in the depressed person's condition and treatment since relatives do not possess the proper medical knowledge. Not taking relatives' experiences seriously may also put patient safety at risk because essential information may not come forth, *e.g.* the side effects of pharmaceuticals.^[27,28] By contrast, Nordby *et al.*^[3] found that the staff acknowledged the importance of the relatives' contribution when it comes to knowledge about the ill person.

Our findings show that relatives are encouraged to get in touch when necessary, but they are not often actively invited into collaboration. In accordance with other studies,^[3,4,28,29] the relatives preferred the staff to take responsibility for inviting to collaboration. The reason for not involving relatives may be that the ill person does not want to put an extra strain on them.^[30] Health professionals' misconceptions of the law of confidentiality have also been reported.^[31] The nurses being afraid of acting illegally may be another reason for not involving relatives.^[32] Additionally, the patients' attitudes towards involving the family has been found to depend on the health professional's encouragement and whether they perceive this as being essential.^[33,34] Due to a conflict of loyalties, paying attention to both the relatives and patients may pose an ethical dilemma for the nurses, particularly if the relationship between the patient and the relatives is difficult.^[32] In our study, the relatives often assessed the patient as being more depressed than the patient did him/herself, which may pose a dilemma for the nurses when they must find a balance between multiple concerns. Culture and tradition which solely focus on the patient in psychiatric hospital care are identified as barriers toward nurses for involving the family in the caring process.^[34] As the patient is their main responsibility the focus is on building and keeping a trusting alliance, which constitutes the basis for a therapeutic relationship.^[32] Lately it is highlighted that persons of importance for the patient should be included in the care.^[34,35]

On the one hand, it is a relief for the relatives that the depressed person is hospitalized, but then come other concerns. This seems to be not only in the context of how

they perceive the staffs' availability for the person who is depressed, but also for the relatives themselves. A closer and more inclusive collaboration with health professionals was found to be important, which corresponds with Perreault *et al.*^[51] and Schröder *et al.*,^[28] who found collaboration to be a key element and predictor of relatives' satisfaction with the mental health services. According to Rowe^[36] and Weimand *et al.*,^[37] collaboration should be characterized by a more empathic communication in which mental health-care personnel encounter relatives with openness and interest. In Kim's^[38] typology of theoretical domains for nursing, the three phenomena of contact, communication and interaction are highlighted in the Client- Nurse domain. These phenomena should also be considered when nurses encounter the relatives of depressed patients in mental health care. Kim states that the relationship should be characterized by a sensitivity, mutual communication and understanding of the client needs according to their situation. This may be in accordance with achieving content continuity, which Ewertzon *et al.*^[39] described as creating confidence and mutual information about the patient's condition and consideration of treatment and care. Because the relatives often perceive the situation differently from the mental health professionals, bringing up relatives' perceptions of the person's depression enables the possibility to agree on a common goal. This will also help the relatives to feel safe and confident in the situation.

The need for continuity, *i.e.* mental health personnel knowing the patient, was also highlighted in the present study. Ewertzon *et al.*^[39] described this as individual continuity, which in our study refers to encountering a nurse who knows the person with depression and who follows up throughout the course of the treatment. A smooth flow of information between the different levels of treating institutions and therapists may be secured through a responsible nurse.

Methodological considerations

In terms of trustworthiness, dependability, credibility, confirmability, transferability are all issues that need to be considered.^[40] The first author's profession as a mental health nurse enabled her to obtain rich data from all the informants, and she performed all the interviews (dependability). Concerning the researchers' preconception of the phenomenon, they strived as far as possible to set them aside. The participating researchers' different competencies and experiences were important in all stages of the analyses (credibility). To strengthen the confirmability, accounts of the analysis process are described in order to establish an "audit trail", and quotations were used to strengthen the conceptions and descriptive categories. To ensure variation in the sample, the informants represented different ages, gender, relationships and levels of education. The findings in this study may contribute to relevant knowledge to other groups of relatives in similar contexts (transferability).

5 Conclusion

Relatives described uncertainty as to whether the person with severe depression received a high quality of care due to a lack of continuity and varying competence among the mental health personnel. Their experiences about the person with severe depression were not acknowledged by the mental health personnel as a matter of course.

Recommendations for practice are that mental health professionals should initiate collaboration with- and support to relatives, and take their knowledge into account in the treat-

ment and care of the person with severe depression.

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Conflicts of Interest Disclosure

The authors report no conflict of interest, as the authors alone are responsible for the content and writing of this paper.

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