

‘Responsible, but Still not a Real Treatment Partner’: A Qualitative Study of the Experiences of Relatives of Patients on Outpatient Commitment Orders

Bjørn Stensrud, RN, RPN, MMHC

*University of Tromsø, Department of Community Medicine, Faculty of Health Sciences, Tromsø, Norway,
and Innlandet Hospital Trust, Brumunddal, Norway*

Georg Høyer, MD, PhD

*University of Tromsø, Norwegian Research Network on Coercion in Mental Health Care and Department
of Community Medicine, Faculty of Health Sciences, Tromsø, Norway*

Arild Granerud, RN, RPN, PhD

*Hedmark University College, Faculty of Public Health, Elverum, Norway and Innlandet Hospital Trust,
Brumunddal, Norway*

Anne Signe Landheim, PhD

*Innlandet Hospital Trust, Norwegian National Advisory Unit on Concurrent Substance Abuse and
Mental Health Disorders, Brumunddal, Norway, and University of Oslo, SERAF-Norwegian Centre for
Addiction Research, Oslo, Norway*

The aim of this study was to explore relatives’ experiences when their family member is under an outpatient commitment order. A descriptive and exploratory approach was used based on qualitative interviews with 11 relatives. The relatives felt they had responsibility for the patient, but experienced a lack of recognition for their contribution to the treatment. Relatives paid little attention to coercion, but were more concerned about whether the follow-up care improved the patient’s social functioning. They further reported an unmet need for information and guidance from healthcare staff to improve cooperation in the patient’s care and treatment.

Changes in mental health care have meant that many people with severe mental disorders live and receive follow-up care in the local community (Molodynski, Rugkasa, & Burns, 2010). This trend has led to increased involvement of these patients’

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Address correspondence to Bjørn Stensrud, Innlandet Hospital Trust, Division of Mental Health, P.O. Box 104, Brumunddal, 2381 Norway. E-mail: bjorn.stensrud@sykehuset-innlandet.no

relatives in their everyday care. Their lives are more closely intertwined with those of the patients and they increasingly share the strain caused by the disorder (Awad & Voruganti, 2008). They find long-term illness with alternating good and bad periods particularly challenging. To cope with this, relatives need to feel accepted as partners in the follow-up care of the patient (Foldemo, Gullberg, Ek, & Bogren, 2005).

Outpatient commitment orders (OCs) have been established in many countries as an alternative to compulsory hospitalisation (Rugkasa, Dawson, & Burns, 2014). OC orders are legal regimes that give clinicians the authority to supervise patients discharged from mental hospitals. The main elements are medication and clinical assessment (O’Reilly, Dawson, & Burns, 2012). The content and criteria of national laws vary with regard to coercive powers and the criteria for imposing OCs (Høyer & Ferris, 2001). In Norway, patients subjected to OC are legally obligated to comply with the treatment (Psyisk helsevernloven, 1999; Norwegian Mental Health Act). OC merely requires that patients who do not come to their appointments with healthcare staff can be forced to comply. If a patient refuses treatment, a separate compulsory treatment decision is necessary. Those who may be subject to OC have a severe psychotic disorder, and typically also a history of treatment discontinuation and many readmissions (Churchill, Owen, Singh, & Hotopf, 2007). Re-hospitalisation from OC requires a simple procedure, where the

responsible clinician can decide to readmit the patient without the need for any new independent assessment. The extent of OC in Norway is unclear, but existing data suggest an increase in its use (Bremnes, 2008). Estimates suggest that one-third of decisions on compulsory inpatient admissions are followed by an OC decision (Bremnes, Pedersen, & Hellevik, 2010).

While many studies have examined the situation for relatives of people with severe mental disorders, few have specifically examined relatives' experiences when a family member is under OC (Mullen, Gibbs, & Dawson, 2006). The relatively few studies published suggest that relatives are more satisfied than patients with OC, particularly because the scheme allows clinicians to more readily intervene in the patient's everyday problems. However, relatives feel little involved in OC and that the scheme challenged their relationship with the patient. They also thought that OC should encompass more areas (Canvin, Rugkasa, Sinclair, & Burns, 2014; Gibbs, Dawson, Forsyth, & Mullen, 2004; O'Reilly, Keegan, Corring, Shrikhande, & Natarajan, 2006). The purpose of this study was to examine how OC is experienced by relatives of OC patients in a Norwegian context.

MATERIALS AND METHODS

This descriptive and explorative study was based on individual interviews using a qualitative content analysis (Graneheim & Lundman, 2004). The method focuses on the subject and the context, emphasising both similarities and differences in sub-categories and categories. The manifest content of the relatives' stories about their experiences with OC was interpreted to find the latent message.

Recruitment and Setting

The study was conducted in two counties in Eastern Norway with a total population of 383,000. The counties consist of small towns and rural regions. Inclusion criteria were a minimum of 6 months' experience as relatives of an OC patient living in those counties; age of 18 or older; and the ability to communicate in Norwegian. Relatives were people whom the patients defined as their relatives. We first identified all patients on OC fulfilling the inclusion criteria and living in the catchment area, resulting in a total of 33 patients. As a condition for ethical approval of the study, informed consent from the patients was required before the relatives could be asked to participate. Accordingly, patients were asked by their treating psychiatrist to consent to their relatives' participation, resulting in 11 consenting patients.

Participants

The researcher invited the relatives of consenting patients in writing to participate in the study. All relatives except two agreed to be interviewed, and a total of 11 relatives of nine patients were included. The sample consisted of eight women and three men: four parents, four siblings, one wife, one daughter and one brother's wife. Of the 11 participants, two relatives of one patient

were interviewed together and two relatives of another patient had separate interviews. Ages ranged from 20 to 83 years. Two were students, two had regular work, six were seniors, and one was on social welfare benefits. All relatives lived in their private homes. Five relatives lived in other counties than their family member on OC. Three relatives lived with their spouse and, in one of these cases, also with the patient. In the other cases, relatives and the patient lived at different locations. Four of the relatives' family members lived in supported housing and four in their own flats. All relatives had regular contact with their family member, some on a daily basis and no one less than several times a month. All participants had more than 5 years' experience as relatives of patients with a severe mental illness using mental health services and more than 1 year as relatives of an OC patient.

Data Collection

The data collection consisted of one in-depth interview with each participant except in the one case where two relatives of the same patient were interviewed together (Kvale & Brinkmann, 2014). The interviewer used a theme-based interview guide and started by asking the participants to share their experiences of living as relatives of a patient on OC. Their stories were followed by the researcher asking them more specifically to elaborate on relevant key topics: everyday life, follow-up from hospital and mental health services in the community, and their experiences with the patient's treatment. All interviews were conducted between September 2013 and August 2014. Five took place in the participants' homes, three in a hospital setting and two in community mental health centres. All interviews were conducted by the first author, lasted 45–70 min and were transcribed verbatim.

Analysis

The analysis was performed in steps as described by Graneheim and Lundman (2004). First, the interviews were read through several times. Each interview was read as a whole, and then sub-divided by identifying meaning units in the transcribed text. The participants' experiences, coping strategies and assessments of their own situation were emphasised (Creswell, 2013). The next step was to condense the meaning units referring to the same content area in the text. This condensed text was labelled as an indicator, covering the intended meaning. The third step was to sort the indicators into 10 sub-categories and then into five categories. The categories were descriptive and understood as expressions of the manifest content in the text. The last step was interpretative, creating a theme linking underlying meaning from the indicators, sub-categories and categories together, to a new level of understanding. This was understood as an expression of the latent content of the text (Lindgren, Sundbaum, Eriksson, & Graneheim, 2013).

To enhance trustworthiness, context and the analytical steps are outlined (Creswell, 2013). Sub-categories, categories and the main theme were compared with the interview data to ensure

that they covered the participants’ intended meaning. The steps in the analytical process were also discussed in the research group to ensure a common understanding. Sorting the interview data into categories was supported by using NVivo 10 (Alfasoft, Sweden).

Ethical Considerations

The participating relatives were informed verbally and in writing about the study before signing a written consent form. They were told that participation was voluntary and that they could withdraw consent at any time without consequences for themselves or their family member. The information emphasised that the interview was for research, not clinical, purposes. The information sheet contained the researchers’ phone numbers to enable participants to contact them after the interview if needed. All data were kept confidential and stored in a de-identified form. No names are used in the presentation. The study was approved by the Data Protection Officer and the guidelines of the World Medical Association (2013) were followed.

RESULTS

‘Responsible, but Still Not a Real Treatment Partner’

The main study finding *responsible, but still not a real treatment partner* reflects the relatives’ understanding of playing a key role in the patient’s life while also feeling that their experience counted for little in the implementation of the OC. The relatives were little concerned about coercion in treatment. They were concerned about everyday matters and whether follow-up care improved patient functioning. Coercion was only raised if the patient did not improve. The relatives had prolonged contact with psychiatric services, and many experiences of chaotic conditions concerning the patient. They described living under the opposing pressures of the patient’s suffering and the follow-up care of the health services. In their experience, before OC the patient had often relapsed into old patterns after discharge, whereas OC added structure and created more predictability. But relatives also experienced limited support in the context of OC.

The findings will be presented below in terms of the categories. The main theme was based on the relatives’ experiences of OC according to the categories: *improved predictability through increased patient stability*; *focus on medication experienced as of limited help in everyday life*; *inadequate communication as a barrier to cooperation*, *impact on relatives’ everyday life*; and *still feeling responsible*. The summary is presented in Table 1.

Improved Predictability through Increased Patient Stability

Most relatives described the patient as more stable after OC commenced. They found their own lives to be more predictable and felt more secure because the patient was under a binding

follow-up scheme. Several stressed the importance of stable medication and continuity in contact with staff:

The OC team has been there the whole time and kept this under control. So that’s something we’ve benefited from. We can’t see everything either, as parents. We have our everyday lives, and our jobs, so it’s fine that people come from outside and try to get things into perspective. What’s been positive is that we’ve felt confident that there are at least some people dealing with this, behind it and steering it a bit. That’s been good.

Relatives believed OC provided a more robust network and therefore relief in their everyday lives. The possibility of readmission with a simplified procedure reassured them. Many recalled experiences before OC where they felt that the patient had gone too long without suitable follow-up measures. Some relatives mentioned the fact that the patient could easily get a relief stay in hospital. Such stays were voluntary and took place while the patient was under OC. The relatives said that they provided relief for the family and alleviated long periods of illness. OC gave them greater freedom because they had others to share the responsibility with:

I do feel OC as a relief, I must say. That’s the right word, I think. There are more people to support us now. Because my sister is functioning so poorly. I mean, all the time you want – you hope it’ll work. But it’s not like that, I just have to face up to it.

Many relatives described feeling helpless before OC when the patient made bad choices unhindered. They believed OC helped them feel at ease because they knew the patient was now being followed up. Several relatives emphasised that OC should have been started earlier because it could have prevented incidents they were still struggling to cope with, and without which the patient would have had a better basis for recovery. Such situations were particularly related to social conflicts and problems with managing money. One stress factor specifically highlighted was the unease they felt about the patient’s negative thoughts and fears that the patient might commit suicide.

Most relatives thought the clinicians, backed by an OC order, should have intervened earlier when the patient’s functioning deteriorated. They also thought that OC should allow for intervention in additional aspects of the patient’s life. Examples mentioned were problems with order and cleanliness and the lack of social activities. No relatives felt stigmatised from having a family member under OC, but several said that the patient was stigmatised in the local community. Relatives experienced uncertainty about responsibility when the patient was under OC. They saw that the patient needed help, but felt unsure about whether the clinicians would share in the responsibility that family members had previously had. In their experience, the staff did not always follow up:

That’s been the problem all along, whether he should have medication or not. And it’s been a predicament as parents. [NN] might have been given a bit too much leeway by the doctor. The doctor’s opinion was he should have medication, but he’s kind of renounced

TABLE 1
Main Theme, Categories, Sub-categories and Indicators Showing Participants' Experiences as Relatives of OC Patients

Indicators	Subcategories	Categories	Theme
OC implies that healthcare services have responsibility	OC gives relatives others to share the responsibility with	Improved predictability through increased patient stability	Responsible, but still not a real treatment partner
OC supports us, we feel more freedom through less responsibility			
Earlier OC decision would have prevented unfortunate situations			
We're worried about lack of content in patient's everyday life.	OC should have been established earlier		
We miss effective alternatives to medical treatment	OC focuses strongly on medication treatment	Focus on medication experienced as of limited help in everyday life	
We find the patient gets worse without medication	Use of coercion is linked to medication treatment		
Forced medication is fine if the medicines work			
We lack information	We feel our opinions count for little	Inadequate communication as a barrier to cooperation	
Our observations are not important			
We experience confidentiality as an obstacle in communication	We must act in crises with insufficient knowledge		
Pressured between own lives and patient's illness	Everyday life must be adapted to demands and expectations	Impact on relatives' everyday life	
I'm a carer and must suppress my own needs	Attention on patient's situation		
Different understandings within family cause conflicts			
We feel uncertain because OC alters roles of responsibility	You have to rely on yourself and your own assessments	Still feeling responsible	
We don't know which clinicians are responsible			
Can we trust the clinicians to follow up?			
We focus on everyday functioning			

responsibility and let him look after himself. So this has been a difficult thing to deal with as relatives.

Many relatives said that the use of OC was correct when they felt that the patient functioned badly. They believed the scheme was in the patient's best interest, a necessary measure when the patient was unable to cope with everyday life. But they were also worried about the future because the patient had few activities with people other than the staff. They saw that the patient lived

an isolated life with little motivation to change. They missed the reassurance that the staff would stay the course with the patient.

Focus on Medication Experienced as of Limited Help in Everyday Life

All relatives believed OC provided a structure that ensured the necessary medication. Several had previously experienced periods of poorer functioning after medication was discontin-

ued. But they did not find that medication helped the patient recover:

I think there's too much focus on medication. It's okay that he takes medication as long as he needs it. But it must be assessed all along, and it is in a way. When he still takes large doses of many kinds for three years and it has no effect? Just the same merry-go-round. Without dropping it and trying out something else.

Some relatives had believed the medicines would help, but gradually became more critical of both efficacy and side-effects. One stated that OC cemented the problems because it locked staff in a medical understanding. Several missed a holistic approach and could only support forced medication as one of several measures:

Basically after discharge there should be something that improved his everyday life. And that part's missing. His life won't be improved by moving to [city] now. With medication based on a compulsory paragraph. I think he should be at an activity centre that could have helped. With a psychologist, physical exercise and the chance to socialise. The measures should be directed more towards letting the patient see possibilities. [Son] sees no possibilities with antipsychotics. Then we need to find other things that might give a response to the real problems. I think being out with other people, outdoors in the countryside and experiencing physical exertion could get rid of the pattern of chaos in his head that's constantly bothering him. I think the physical part is important, just as important as medication in fact.

Most relatives knew little about the medication. They felt that medication was a conflict area; the patient was often critical, while the clinicians through the OC order underlined the necessity of medication. Relatives were unhappy that the medication could seem random and was not followed up by the staff as they expected. Their dilemma was a fragile belief that the medicines improved the patient's condition, while this understanding was challenged by the patient's negative experiences. They found that the staff expected them to support the medication. They sought better information from doctors and healthcare staff about medicines and alternative approaches. Forced medication was a troublesome recurring theme in their contact with the patient.

Inadequate Communication as a Barrier to Cooperation

All relatives described the burden of living with the patient's alternating good and bad periods. OC did not alter their experience of living under strain. Just as before, the relatives found that communication was split between patient-clinician and patient-family. The inadequate communication between staff and families was partly because the patient often did not want to involve relatives, but mainly because the staff did not listen to or took account of the relatives' experiences:

It's tough to find that – you have sick children, so to speak. The toughest thing I feel is that the dialogue with the psychiatric staff maybe isn't how I feel it should be. It can be ok, I'd say, but often you feel you're being put aside a bit. And maybe not being listened

to about how you experience the situation then. I reckon that's the toughest part.

Relatives had difficulty in finding their role when the patient was under OC. They felt they were inconveniencing the staff when they needed to argue for their view that the patient's functioning had deteriorated. Several missed more information about the scheme and having a contact person. A problem area for some relatives was the staffs' use of confidentiality. They felt that the way it was practised made it a hindrance that complicated life for themselves and the patient:

I often have the impression that the health services are using confidentiality against me. And it's awfully annoying and tiring. When you've been with a patient like my daughter for many years and talked to lots of doctors, lots of nurses, lots of helpers from all directions – and then you get a critical situation and you don't know what's going on. It's so frustrating. I've kept on ringing but I just meet that brick wall.

One relative called the clinicians cowardly for hiding behind confidentiality to avoid difficult talks. Relatives felt they lacked the legitimacy to intervene, since OC created a patient-clinician relationship they felt excluded from. Yet they still felt responsible. Particularly parents recounted the stress of experiencing a lack of cooperation when they saw their children struggling with everyday coping.

Impact on Relatives' Everyday Life

All relatives said that OC gave the patient a framework that affected their everyday life:

We've had a lot of responsibility in bringing him, waking him up when he had to meet the team, being present when the team came because he wasn't sure. We've had to go out of our way an awful lot. It's partly affected our jobs. I've had no problem getting time off to look after things at home. My wife maybe hasn't taken so much time off. In periods when he was really bad, he put a lot on his mother's plate. So it's been tough for her. I've actually had to deal with most of it, as a father.

Relatives felt pressure to contribute, and saw the caregiving tasks as ever-present. Many described a feeling of falling short:

I have to teach myself how to live my own life, and that's quite reasonable. But at times I'm kind of – I wish I could manage more. And had the chance to. So it hurts a lot. When I'm the only one. No brothers, sisters, nobody else. So it kind of becomes a strain then.

Several relatives said they had the role of go-betweens, defending the OC when talking to the patient and the patient's view when talking to clinicians. Their stories showed that they felt this role was not acknowledged. Instead, they felt taken for granted, and that the staff related to the patient without considering how OC affected relatives' lives.

Some relatives described how OC could generate family conflicts. Family members had different views of how much one should be involved in the patient's life. Several patients had accused relatives of failing them in choosing the OC support.

However, the stories also showed that they found a kind of balance and that discussing problems with the patient was easier under OC. But they still felt pressured between the medical assessments and the patient's desire for change. Any conflict between patient and clinicians was felt by relatives to be an additional burden. The narratives showed that such situations could create family tensions that went beyond the situations themselves.

Still Feeling Responsible

Many relatives emphasised that despite OC they still had to resolve situations in the patient's and their own lives on the basis of their own understanding and experience:

I think actually the team could back us up a bit more. Because we sometimes haven't really had much information. Sometimes by chance for natural reasons like illness and vacation. And when the emergency happened last summer, the doctor and primary contact were on holiday. So then we're the ones who have to take action. All the time. And we're a bit fed up with it. And before he was admitted, we saw he'd got worse and we told the team. But they didn't see what we saw. So we don't completely trust [son], and we don't completely trust the team, so we have to try to rely on ourselves.

Several relatives experienced a lack of continuity during OC; decisions were not communicated or not followed up. One felt his situation to be more difficult after OC was established because he felt pressure to follow-up the patient's obligations. Relatives mentioned many meetings with staff where the intentions were good, but the problems were inadequate follow-up and implementation in practice.

Responsibility and follow-up, more than the coercive care, dominated the relatives' descriptions:

We're the ones pulling the strings all the time. And that's the dilemma we're living in, I feel. We could have just not given two hoots and trusted in what the doctor does, but we've seen this sometimes going the wrong way. To be honest, I haven't thought very much about him being under compulsory care. It's there, but our everyday things are more than enough.

Most relatives found that OC had a positive effect on their lives, but also that it did not solve all their problems. All described their relationship with the patient as the continuity in the treatment. Their contact with clinicians was often quite limited. Some relatives were uncertain about who the patient's doctor was and said that their only contact with the hospital was a decision letter they received every 3 months. Several had rung the hospital without getting through to those responsible. Their experience was therefore that they found some support in the OC framework, but still needed to rely on their own judgement in parallel.

DISCUSSION

The main study finding was that relatives of OC patients still played a key role in caring for the patient. Relatives believed OC stabilised the patient's situation and made their own lives

more predictable. At the same time, they were side-lined and found their opinions to count for little in contact with clinicians. Doornbos (2002) showed that it can be stressful for relatives to be pressurised between the patient, healthcare staff and their private life. Our study showed that relatives had to balance their own experiences with the patient's wishes and the clinicians' requirements. They experienced contradictory expectations that created uncertainty about their own role and responsibilities. They also found that the clinicians expected them to support the treatment.

Relatives did not distinguish between general experiences with mental health care and specific factors attributable to coercion. The important point for them was that the patient received the best possible treatment. While the opportunity for individual freedom is often raised in the debate about the use of coercion in mental health care, these relatives expressed little concern about OC as a freedom-limiting intervention. They instead would prefer a holistic approach where coercion was used in different areas to ensure patient participation in social activities and improve the patient's self-care and living skills. Relatives often thought OC should have been established earlier to limit the consequences of bad periods. This demonstrates greater concern about normalising life than about a principled discussion on forced treatment. A surprising finding was that no relatives related OC to the idea of danger. The findings of the study by Torrey and Zdanowicz (2001) connecting OC to improved public protection are therefore not reflected in our results.

Relatives experienced the support of a more robust network and the relief offered by a sharing of responsibility. But different understandings of OC could create conflicts. Divergent experiences of OC are found in other studies. O'Reilly et al. (2006) showed that relatives had a positive view of OC and found the scheme necessary to cope with situations that could arise due to the patient's condition. But relatives also felt that they had to carry the burden when the patient did not receive adequate follow-up care. Relatives felt that the limitations of OC made the scheme less effective than they wanted. They nevertheless found that OC brought structure into the chaos created by the patient's lack of insight. Mullen et al. (2006) found that relatives felt that OC provided improved stability that helped the patient gain insight. This insight improved cooperation within the family and between family and clinicians. Canvin et al. (2014) revealed considerable variation in the understanding of the consequences of OC for those involved, and that this uncertainty could unsettle relatives' view of their role in relation to the patient. The same study emphasised the lack of treatment options beyond medication, and asked whether the patients would have made the same progress with closer monitoring without coercion.

Relatives felt a sense of security with OC, both because follow-up care was ensured and because it could prevent bad choices. At the same time, they were unable to shake off the feeling of often having sole responsibility for the patient. Topor et al. (2006) showed how the family is an important treatment arena.

Ewertzon, Lutzen, Svensson, and Andershed (2010) found that the involvement of relatives in treatment based on a holistic understanding reduced the relatives' burden and enhanced the patient's recovery process. Our study showed that relatives experienced OC as of limited help. If relatives are to be a treatment resource, clinicians must provide for a strengthening of their role (Kaplan, Turner, Norman, & Stillson, 1996). As Weimand, Hedelin, Hall-Lord, and Sällström (2011) showed, relatives of people with severe mental disorders need support to master their role as relatives. They need to feel that their experience is acknowledged and worked on. Hallam (2007) found that treatment cultures which exclude relatives, can lead to a climate of cooperation that alienates the family from the patient's life. Such a development could make relatives distance themselves from the patient to protect themselves rather than involving themselves to promote the patient's recovery process. Conversely, contact with relatives can enhance the social functioning of the patient (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006) and reduce the risk of relapse (Pitschel-Walz, Leucht, Bauml, Kissling, & Engel, 2001). These findings underscore the importance of involving relatives in treatment. Clinicians must make themselves more available to relatives, and take on responsibility for solving the obstacles to cooperation identified in this study. This would prevent relatives feeling left to themselves in follow-up care, as many experienced in this study.

Relatives lived in hope that the medication would make the patient recover. Meanwhile they worried about the patient's inadequate coping. Their experiences with the patient's medication were both positive and negative, and they often felt challenged by the patient's negative experiences. Relatives' experience finds support in studies showing that the long-term effects of psychosis medications may be overstated (Leucht et al., 2012). Some studies explain relapses as a consequence of long-term medication (Harrow & Jobe, 2013; Wunderink, Nieboer, Wiersma, Sytma, & Nienhuis, 2013). Different understandings of the development and treatment of mental disorders can provide useful perspectives on the relatives' situation. A medical model understands mental disorders as diseases where specific treatment is implemented on the basis of the diagnosis (Stuart, 2005). Health professionals have the position of experts and the patient receives treatment. In this understanding, relatives have little significance beyond supporting the medical treatment. The medical context can thus be perceived as exclusionary (Outram et al., 2015). A social causal explanation would place greater emphasis on the social context where the person may develop mental disorders through stress or lack of social support (Scheid & Brown, 2010). In this understanding, the involvement of significant others will be very important. OC formalises the patient-clinician relationship and emphasises the medical approach, while the relatives maintain contact with the patient through everyday interaction. This relationship has a social psychiatric basis. In this context, relatives experienced a dilemma, feeling responsible for the patient's situation but also finding that the staff understood their contact

as supporting the treatment rather than having an independent meaning.

Relatives found the medical treatment to be the central instrument in OC. Stensrud, Høyer, Granerud, and Landheim (2015) found that OC patients had the same experience. Sjostrom, Zetterberg, and Markstrom (2011) pointed out that OC can encourage a medical understanding. Guidelines for the treatment of psychotic disorders do not support a view of priority for a medical model (Helsedirektoratet/Norwegian Directorate of Health, 2013). Priebe, Burns, and Craig (2013) maintained that mental illness should be more readily understood and addressed in the light of a social paradigm. This view supports the relatives' wish for the patient's poor functioning to be addressed in more ways than with medication.

Limitations

This study was conducted in a limited geographical area, with the inherent risk that it has captured a local practice that differs from other areas. Only relatives of patients consenting to their participation were included. It is reasonable to assume that in the cases of consent the patient-family relationship was based on trust and cooperation, whereas lack of consent may indicate a more complicated relationship. The absence of relatives of patients who objected to interviews may have influenced the direction of the findings. A limitation of the study is a relatively small sample. This limitation is somewhat compensated for as all relatives had close contact with the patient over a long period of time. The sample also consisted of relatives with different relationships to the patient. This could strengthen the analysis by providing a broader range of experiences. A small and heterogeneous sample could represent a limitation in that the material is not sufficiently diversified for different categories of relatives. Further interviews might have provided additional perspectives. Nevertheless, we found that the later interviews confirmed previous themes, without providing new perspectives. The objective of the study was not to generalise, but to use a qualitative approach to describe key experiences in the lives of relatives of OC patients (Creswell, 2013). The findings are supported by other studies, suggesting validity beyond the participants in the present study.

CONCLUSIONS AND CLINICAL IMPLICATIONS

The main finding was that relatives of OC patients felt that they were *responsible, but still not a real treatment partner*. The OC framework gave them a sense of security. They felt that OC ensured the medical treatment and stabilised the patient's life. At the same time, they felt sidelined because their experience was not taken into account in the implementation of the OC. Relatives were little concerned about coercion, but focussed instead on everyday functioning. They accepted coercion in periods when the patient's functioning was severely impaired. However, the relatives' experience was that medical treatment did not solve the problems they lived with. They worried about

the lack of meaningful activities in the patient's life, and therefore believed that OC should encompass a broader approach to the patient's situation. Relatives faced contradictory expectations, being torn between the patient's desire for support of his/her choices and the clinicians' desire for support of the medical treatment. Such divergent expectations were experienced as stressful, especially when patient and staff were in conflict about OC. The relatives' situation was challenged in that they still represented the main continuity in the patient's life even in OC. At the same time they could not completely rely on the staff keeping to agreements as they wanted. They had to rely on themselves. Recognition of relatives' need for involvement, support and guidance is a prerequisite for good cooperation in OC planning and implementation. Healthcare staff must take better account of the situation of patients' relatives; they represent an untapped resource in the patient's otherwise vulnerable network. Including their expertise and experience can enhance treatment.

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