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Microdecisions instead of coercion: patient participation and self-perceived discrimination in a psychiatric ward

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ABSTRACT

Aims: Patients may experience unfair reception when in contact with psychiatric services. The aims are to illuminate these perceptions, and the extent of inpatients' involvement in their care, and if degree of involvement depends on compulsory or voluntary care. Furthermore, we sought to determine if an educational intervention for staff members, including systematic listening and offering the inpatients involvement using microdecisions, affects the inpatients' experiences and the use of coercion.

Materials and methods: We used a naturalistic setting case control design in two psychiatric wards for one year, including all inpatients ($n = 685$) of which 458 took part of the microdecision intervention. Structured direct interviews were carried out with inpatients based on the Discrimination and Stigma Scale (DISC), Dyadic OPTION, and CollaboRATE instruments before ($n = 19$) and after ($n = 46$) the intervention. Frequencies of coercive measures before and after the intervention were compared ($n = 685$).

Results: Respondents subjected to the intervention experienced less discrimination related to psychiatric care compared to responders not subjected. Tendencies of improvements post intervention were found for some aspects of involvement, as attention to concerns and possibilities to ask questions. A decrease in the use of coercive measures at three and six months after the start of the intervention was observed.

Conclusion: Results suggest that the intervention could decrease the inpatients' experiences of discrimination during psychiatric care as well as the use of coercion in the service. The Dyadic OPTION instrument showed a mixed picture with results implying improvements in some areas and impairments in others.

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Mental illness; stigma; discrimination; DISC; patients' participation

Introduction

The right for all people to be treated equal in the healthcare system regardless of gender, socioeconomic status, ethnicity, and level of mental function, has been pointed out by the Swedish Association of Local Authorities and Regions and the National Board of Health and Welfare [1]. This applies not least in the field of mental health [2]. The Swedish government has for several years prioritized mental health and psychiatric healthcare [3] and has started numerous initiatives through Mission Mental Health, which is assigned to improve the cooperation between the government and the municipalities and regions that are responsible for the delivery of services [4]. One of the projects, *Better care – less coercion*, aims at reducing the need for coercive measures during psychiatric inpatient care.

Many of the working parties within *Better care – less coercion* have in different ways tried to increase patient participation in care situations and in the communication between staff members and patients. One of the included region assemblies states that their survey shows that patients and

their relatives' experiences are neglected in the psychiatric care situation [5]. The National Patient Survey from 2018 [6] confirms the insufficient participation of patients and relatives. Only one third of the 2924 responders felt that they were involved to the extent that they desired. Within Region Västerbotten, the results were even worse, with only a quarter of the responders feeling involved to the extent that they desired. Less than one third nationally, and one fifth of responders in Region Västerbotten, thought that their relatives were involved by the health services to the extent that they had wished. Approximately half of the responders experienced a personal reception characterized by empathy, both in Sweden as a whole and in Region Västerbotten. The improvement of psychiatric services has been prioritized in other Nordic countries as well. The Danish government has addressed barriers to continuity of care in the mental health system and brought interventions into action, but concerns have been raised regarding focusing on the organization and not taking the participation, perspectives and urgencies of the patients into account [7].

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Discrimination due to mental illness and poor personal reception are known to contribute to psychiatric patients' feelings of not being a valid part in the encounter with health services [8], while everyday life activities at the wards that bring inpatients and clinicians together tend to decrease self-perceived stigmatization [9]. Several studies have shown that most psychiatric patients both expect and experience poor reception or are submitted to actual discriminatory acts in their contact with the health services [10–13]. There seems to be a negative correlation between the degree of self-perceived discrimination and the degree of self-perceived participation [9]. Also, coercive measures have been shown to increase the experience of being discriminated against, and to decrease the perception of participation to a minimum while a lower degree of self-perceived discrimination seems to reduce the need for coercion [14]. As a follow-up to a national Swedish campaign against mental health-related stigma [15] inspired by the British program Time to Change [16], several surveys using the Discrimination and Stigma Scale (DISC) were conducted during the period of 2011–2013 [11]. The results provided important data about overall experiences of discrimination and unfair reception and showed a high degree of discrimination within the health services but an even higher degree of self-hindering due to anticipation of unfair reception.

This study aimed to examine self-perceived stigmatization, unfair reception, and patient participation among psychiatric inpatients using survey-based, structured, direct interviews before and after an intervention consisting of training of the psychiatric personnel on how inpatients are received and how they are given opportunities to participate in their own care. Our hypothesis was; the degree of perceived participation would increase after the intervention, whereas the perception of unfair reception and the amount of coercive measures would decrease. This study sought to answer the following questions: 1. *To what degree do psychiatric inpatients experience discrimination and unfair reception within the psychiatric health care system?* 2. *To what extent do the inpatients feel involved in their care?* 3. *How does a training intervention for staff members affect the experiences of discrimination and participation, and the use of coercion in the service?* 4. *Are there systematic differences in inpatients' experiences between those under compulsory care versus those under voluntary care?*

Materials and methods

This naturalistic study used a case control design and was conducted in two psychiatric wards during a time period of 12 months. All inpatients admitted to the two wards during this time-period were included. The intervention was carried out after six months. Structured interviews were performed in two participant groups drawn from the patient population; (1) inpatients subjected to the intervention (intervention group) and (2) inpatients not subjected to the intervention (comparison group). Interview data were compared between the two groups, as well as coercion statistics pertaining to before and after the onset of the intervention.

Instruments

Structured direct interviews [17] were conducted with 65 of the inpatients based on the DISC [18], Dyadic OPTION [19] and CollaboRATE [20]. DISC is widely used internationally as well as in Sweden. The Swedish version is validated through retesting using quality interviews [11] analyzed with thematic qualitative content analysis [21]. The instrument consists of subparts covering different aspects of discrimination and stigmatization related to mental illness. The 32 questions focus on whether the responders have experienced discrimination, self-stigma, or self-restraint based on expected stigmatization or discrimination, whether they have been able to overcome discrimination, and whether they have experienced positive discrimination. Responders were instructed to think about the previous 12 months when answering the questions. The Swedish version of the Dyadic OPTION and CollaboRATE instruments have been validated and psychometrically analyzed among users of the Social Services [22]. Both instruments aim to measure the degree of patient participation in health care and the patient's perception of the amount of effort made by health professionals to understand the patient's situation, difficulties, and needs. The Dyadic OPTION and CollaboRATE instruments were used to evaluate the responder's last psychiatric episode as an inpatient.

Sample

The material used for coercion statistics included all 227 inpatients at the Psychiatric Clinic at Skellefteå regional hospital, Region Västerbotten, Sweden, during the six months period before the intervention started, and all 458 inpatients at the same wards from the six months period after the start of the intervention. All 458 inpatients from after the intervention start took part in the intervention. The psychiatric service in Skellefteå is a part of the public Swedish health-care system. Responsibility for the care lies with Region Västerbotten, the regional assembly. The population base is of mixed type with both rural and urban parts and the wards receive patients from the catchment-area with no restrictions regarding psychiatric diagnoses. Mean length of stay for inpatients at the service, who has in total 30 beds, is 19 days. There were no differences in mean length of stay when comparing the inpatients during the entire study period to the inpatients from before and after the intervention start. There are no private psychiatric inpatient services in the region.

Inpatients recruited to structured direct interviews, presented in Table 1, included 65 persons of whom 42 persons were treated voluntarily and 23 were treated under the Compulsory Mental Care Act [23]. The responders included 24 men and 41 women ranging in age from 18 to 84 years with a mean age of 43 years and a median age of 41 years. Self-reported main diagnoses were affective syndromes, neuropsychiatric disorders, psychotic disorders, and other diagnoses such as eating disorders, substance use disorders, and sleep disorders. Three more inpatients were recruited to structured direct interviews, but they chose to interrupt their participation, and five inpatients chose to respond only to

Table 1. Responders, structured interviews.

	Intervention group (n = 46)	Comparison group (n = 19)	All participants (n = 65)
Men	18 (39%)	6 (32%)	24 (37%)
Women	28 (61%)	13 (68%)	41 (63%)
Age, mean (median, Q1, Q3)	40 (40, 28, 52)	48 (49, 30, 60)	43 (41, 29, 53)
Compulsory care	13 (28%)	10 (53%)	23 (35%)
Self-reported main diagnosis			
Affective syndromes	20 (43%)	14 (74%)	34 (52%)
Neuropsychiatric disorders	13 (28%)	2 (10%)	15 (23%)
Psychosis disorders	6 (13%)	2 (10%)	8 (12%)
Others	7 (15%)	1 (5%)	8 (12%)
Self-reported diagnoses, all			
Affective syndromes	40 (87%)	14 (74%)	54 (83%)
Neuropsychiatric disorders	17 (37%)	4 (21%)	21 (32%)
Psychosis disorders	6 (13%)	4 (21%)	10 (15%)
Others	26 (57%)	4 (21%)	30 (46%)

DISC but not to Dyadic OPTION or CollaboRATE. The study was approved by the regional Ethical Vetting Board in Umeå, Event no. 2016/156-31.

Interviews and intervention

The comparison group of study participants underwent structured direct interviews before the intervention, while the intervention group was interviewed after the start of the intervention. All interviews were conducted close to, or after, the end of the inpatients' care episodes but not later than two weeks after discharge. Two medical students performed the interviews after training. The students were not part of the medical team and could not influence clinical decisions concerning the participants. The intervention included education of the staff members at the ward regarding personal reception and a weekly microdecision survey of the inpatients conducted by one named and accountable staff member per ward. In the weekly survey, all inpatients were individually offered to present three matters they would like to change and one matter they would like to keep as before as well as their level of satisfaction considering the previous week's survey, when applicable. The satisfaction level ranged from 1 - *Dissatisfied* to 4 - *Very satisfied*. The inpatients were instructed that themes in the survey could include all types of areas such as food, the environment, activities, medical care, etc. The survey question themes could be categorized as microdecisions. Microdecisions are small-scale decisions, often about the patient's everyday life at the ward. The primary focus for microdecisions are seldom the actual content of healthcare treatment. The weekly microdecision surveys, part of the intervention, included all inpatients in the wards regardless of whether they were participating in the structured direct interviews or not. During the weekly staff meeting the survey results were reported, anonymized when possible, and the requests were taken under consideration for possible changes regarding content of care and nursing measures at the wards.

Coercive measures

Due to Swedish legislation coercive measures includes forced medication, restraint, seclusion, and restriction of electronics.

Frequencies of coercive measures were collected from the medical records of all inpatients at the wards regarding the time period before and after the intervention start. Thus, the coercion data from the period from the start of the intervention includes all inpatients subjected to the intervention including the follow up survey, irrespective of the patient had been interviewed or not. To enable a more correct comparison between frequencies of coercive measures before and after the intervention, the results have been adjusted for extreme values, and one inpatient was excluded because this single patient accounted for 50 coercive measures during one of the periods and thus deviated significantly from the group as a whole.

Statistical analysis

The results from the direct interviews consisted of ordinal variables and are presented as a summarized description with frequencies of affirmative answers for discrimination based on the subparts of the DISC instrument as well as the mean scores from Dyadic OPTION and CollaboRATE, in order to answer study questions 1–2. To answer study question 3, nonparametric tests (Mann-Whitney) were carried out before the data were dichotomized and analyzed by one-sample chi-square test or the one-sample binominal test. The Chi-square test was used to make the results more intelligible due to the data consisting of categories of yes/no answers. Further, answers from the two groups of participants were compared to each other and analyzed with One-Way ANOVA, which also was used as statistic method to answer study question 4. Since data was considered as ordinal all ANOVA results were crosschecked using Kruskal-Wallis tests, all yielding similar results. Therefore, only the ANOVA results are displayed and discussed. Frequencies of coercive measures from the two interview periods are presented as [Supplementary data](#) to study question 3. Specific items were selected for direct interviews, in order to answer the study questions, and were examined if deviating from the answer *no*. Our primary interest was to illuminate whether or not such a deviation existed, whereas the logistic model could explain why deviation might have occurred. No corrections were made for multiple comparisons since type II errors were deemed more likely than type I errors, due to small sample size, following contemporary recommendations [24]. Significance level was set to $\alpha = .05$ and IBM SPSS Statistics Version 25.0 [25] was used to conduct the analyses.

Results

Disc

Of all responders, 81 percent ($n = 65$) stated that they had been treated *unfairly* 'Moderately' or 'A lot' regarding at least one life area during the previous 12 months, and within the category Psychiatric care 34 percent reported unfair reception. Frequencies of unfair reception are listed in [Table 2](#). Responders in the intervention group reported unfair

Table 2. Frequencies of answers indicating unfair reception (“Moderately” or “A lot”) from the DISC instrument and comparison between the two responder groups.

DISC category	Frequencies for reported experiences of unfair reception			Group comparison	
	All participants (n = 65)	Intervention group (n = 46)	Comparison group (n = 19)	χ^2	p
Discriminated against, any question	55 (81%)	40 (87%)	15 (79%)	.42	<.001
Psychiatric care	22 (34%)	14 (30%)	8 (42%)	.37	.013
Friends, family, relationships	38 (59%)	28 (61%)	10 (53%)	.54	.22
Living, neighbors	19 (29%)	14 (30%)	5 (26%)	.74	.001
Education, work	16 (34%)	10 (36%)	6 (32%)	.77	.041
Everyday life	36 (55%)	28 (61%)	8 (42%)	.17	.46
Government, healthcare	38 (59%)	28 (61%)	10 (53%)	.54	.22
Self-stigma	46 (72%)	36 (72%)	10 (56%)	.069	.001
Overcome stigmatization	45 (70%)	30 (65%)	15 (83%)	.15	.002

Table 3. Means for the Dyadic OPTION items and the comparison between the two study groups. Scores are on a scale of 1–4, where 1 corresponds to Strongly agree and 4 corresponds to Strongly disagree.

Dyadic OPTION statement	Mean values			Group comparison		
	Intervention group (n = 42) m (sd)	Comparison group (n = 18) m (sd)	All participants (n = 60) m (sd)	F	Eta ²	p
Made clear that a decision was needed	1.95 (.94)	2.11 (.90)	1.95 (.93)	.77	.013	.38
Described more than one way to manage a problem	2.55 (1.13)	2.39 (.98)	2.50 (1.08)	.27	.005	.61
Offered different sources of information	3.45 (.94)	2.89 (1.08)	3.28 (1.01)	4.13	.066	.047
Discussed different options	2.83 (1.15)	2.82 (1.02)	2.83 (1.10)	.001	<.001	.98
Discussed advantages, disadvantages, and possible outcomes	3.00 (1.23)	2.50 (1.20)	2.85 (1.23)	2.11	.035	.15
Discussed ideas or expectations	2.78 (1.15)	2.83 (.88)	2.80 (1.06)	.030	.001	.86
Discussed concerns or worries	2.48 (1.15)	2.78 (1.00)	2.57 (1.11)	.93	.016	.34
Made sure information had been understood	2.31 (1.07)	2.39 (.85)	2.33 (1.00)	.078	.001	.78
Provided opportunities to ask questions	1.69 (1.00)	2.11 (1.08)	1.82 (1.03)	2.13	.035	.15
Respected the preference to take part in decisions or not	2.31 (1.24)	2.39 (1.09)	2.33 (1.19)	.055	.001	.82
Decision or agreement to postpone making the decision	2.05 (1.13)	2.39 (1.04)	2.15 (1.10)	1.21	.020	.28
Discussed the possibility of coming back to the decision	2.57 (1.21)	3.00 (1.03)	2.70 (1.17)	1.72	.029	.20

reception within Psychiatric care to a lesser extent than the participants who had not been part of the intervention.

Patient participation

In comparing the responses from the comparison group and the intervention group using Dyadic OPTION, there were statistically significant differences only for the statement “Offered different sources of information”, where the intervention group agreed to a lesser extent (Table 3). The remaining data showed tendencies for improvement after the intervention for statements regarding attention to concerns and worries and possibilities to ask questions, among other things. Patients’ level of participation in discussions about advantages, disadvantages, and possible outcomes of the care tended to be impaired after the intervention. The responses to the CollaboRATE questions were all in the mid-range of the scale, which ranged from 0 - *No effort was made* to 4 - *Every effort was made*, and there were no differences between the comparison group and the intervention group.

Compulsory care

No differences were found between inpatients who received voluntary care and inpatients treated under the Compulsory Mental Care Act for any of the three instruments within the

two groups as well as when comparing the intervention and comparison groups. Compulsory care inpatients did not report unfair reception to any greater degree than inpatients treated voluntarily.

Coercive measures

Numbers and proportion of inpatients subjected to coercion, frequencies of coercive measures and means of actions per inpatient exposed to such measures are presented in Table 4. The data include not only the interviewed study participants, but all inpatients at the clinic treated under the Compulsory Mental Care Act. Comparison of both the three month periods before and after the intervention start and the six month periods before and after the intervention start showed a lower mean number of coercive measures after the intervention as well as a decrease in the share of inpatients exposed to coercion, which for the three-months periods dropped from 19% to 12% ($p = .04$). The number of hospital beds increased at the clinic during the year after the intervention start, explaining the higher total number of inpatients.

Weekly microdecision survey during intervention period

The greatest part of the microdecision intervention survey data, 26% of the 217 inpatient responses, concerned how

Table 4. Total frequency of coercive measures during the period before and after the interviewing round, mean number of measures per inpatient exposed to coercion and number of inpatients exposed to coercive measures.

	Before intervention 3 months (n = 117)	After intervention 3 months (n = 241)	Before intervention 6 months (n = 227)	After intervention 6 months adjusted ^a (n = 458)	After intervention 6 months (n = 458)
Coercive measures used, total	50	49	124	148	198
Measures/exposed inpatient	2.27	1.69	2.95	2.24	2.96
Inpatients exposed to coercive measures	22 (19%)	29 (12%)	42 (19%)	66 ^a (14%)	67 (15%)

^aData adjusted for extreme frequency values. One inpatient accounted for 50 coercive measures during the period, thus prominently deviating from the group as a whole.

well one is received, and this was followed by 20% regarding activities, 17% concerning environment issues, and 16% related to food and beverages. Only 8% of the requests concerned medical treatment, 7% concerned information, and 6% concerned therapy. The mean inpatient satisfaction score was 3.12 when the outcome from the previous week's survey was assessed on a scale ranging from 1 - *Dissatisfied* to 4 - *Very satisfied*. Furthermore, the clinicians assessed the microdecision method as easy to implement in their daily work and as rewarding with regards to offering concrete ways to improve the inpatients' situations.

Discussion

To what degree do psychiatric inpatients experience discrimination and unfair reception within the psychiatric health care system?

Patients in psychiatric services often experience situations in which they perceive themselves as being received unfairly or even discriminated against. More than one third in this study felt discriminated against within the psychiatric services, contexts that ought to be characterized by the highest level of competence and acceptance concerning persons with mental illness. Looking at the intervention group, 9 out of 10 answered affirmative to being discriminated against in some way during the last 12 months, which was an increase compared to the comparison group. At the same time the affirmative answers regarding discrimination within the psychiatric services decreased in the intervention group. However, the increase in affirmative answers in the intervention group can mainly be found in responses to questions regarding self-stigma. In fact, a lot of experiences of discrimination were derived from self-stigma and the anticipation of being unfairly received rather than experiences of ongoing discrimination. Perhaps actualizing the field of discrimination, focusing on self-perception and evoking earlier experiences, could explain the increase in the inpatients' anticipation of unfair reception outside the wards.

It is known that there is a link between poor personal reception and the feeling of being discriminated against, and Molin [9] highlights that there seems to be a power imbalance between caretakers and clinicians. When the staff in Molin's study interacted with focus on the inpatients' best, the inpatients reported trustful interactions, and the imbalance seemed to decrease. The results from this intervention study on everyday life suggest, in line with Molin's results, that the quality of the interaction at the ward matters and that the absence of interactions between staff members and

inpatients contributes to the perception of a stigmatizing environment. We suggest that poor reception is connected to experiences of discrimination. There seems, however, to exist a possibility to decrease the amount of perceived discrimination through simple means. When the clinicians systematically listened to the inpatients' requests regarding all aspects of life at the ward, not only concerning medical issues, the frequency of affirmative answers on discrimination within the psychiatric service decreased from 42% to 30%. Many psychiatric clinics and clinicians probably already try to listen to the inpatients' needs and wishes, but perhaps a systematic way to capture these messages can be an instrument, among lots of other measures, for making changes.

To what extent do the inpatients feel involved in their care?

The participation instruments' results show that the clinicians did well with regards to making clear that something needs to be done. However, the clinicians seem to have done less well in offering alternatives and listening to the inpatients' worries. It is possible that the psychiatric service prioritizes its own agenda rather than the agenda of the inpatient and this might partly explain the high degree of self-perceived discrimination. During the intervention, the inpatients reported high satisfaction regarding the outcome of their microdecision requests. After the intervention, the staff members tended to be better at offering opportunities for inpatients to ask questions, at listening to worries, and at giving the inpatients the opportunity to decline alternatives. Therefore, our results could possibly support the hypothesis that personal reception and a higher degree of participation are linked to decreased self-perceived discrimination. The inpatients reported high satisfaction during the intervention, but we were not able to demonstrate this in the results from the instruments meant to measure involvement.

How does a training intervention for staff members affect the experiences of discrimination and participation, and the use of coercion in the service?

The weekly survey probably made it clearer for inpatients as well as for staff members that the inpatients' voices were important, even though not every request could be met. A nonsystematic approach risks an inpatient's request going unnoticed, and this is even more so if the inpatient expects unfair reception due to previous experiences and self-stigma. Furthermore, the amount of coercive measures per inpatient,

and the percentage of inpatients subjected to coercion, decreased after the intervention. Results from the DISC-item regarding psychiatric care and the microdecision survey material collected during the intervention, suggest that a systematic listening and an offering of means for participation in the decision process might contribute to a decrease of the need to use coercive measures.

Are there systematic differences in inpatients' experiences between those under compulsory care versus those under voluntary care?

Voluntary versus compulsory care did not show any influence on experiences of discrimination. Several earlier studies have shown similar results [14,26]. The perception of being well received is highlighted as an important means for patients not to feel violated against. It might be argued that decreasing self-perceived unfair reception by listening to inpatients' requests and thereby allowing for influence on the micro-level might lead to a higher degree of participation regardless of whether the inpatient is receiving voluntary or compulsory care. This, in turn, might be part of the explanation for the decrease in coercive measures found after the intervention. The finding that voluntary versus compulsory care does not affect the perception of discrimination can also be explained by that until a coercive measure is enforced, not much sets compulsory care and voluntary care apart. The inpatients receive the same kind of treatments, usually share the same space at wards and, at least in Sweden, all inpatients are almost exclusively admitted to facilities with locked doors.

Limitations

The design of the study is naturalistic. The everyday life was studied in the natural environment. Therefore, case control was not set up as case control usually is. A lack of statistical power due to small sample sizes increased the risk for type II errors, and some group differences may have been missed. On the other hand, the naturalistic setting and design brings an "ecological validity" to the study. Still, results could be explained by other factors not possible to change in the naturalistic setting, such as inpatient composition at the wards at each period, individual staff members on duty, or patient's severity of disease. Even though the mean length of stay did not differ between the two groups in the study, which could indicate that the disease severity was approximately the same throughout the whole project, no severity data was collected. The fact that the number of beds was increased during the study period is a possible confounder. Together, this makes the possibilities to draw general conclusions limited. Further studies are required to confirm the findings. The results from CollaboRATE did not give much further information about the inpatients' participation in their care, with all responses tending to be in the mid-range of the scale. We kept the integrity of the instruments, following the manuals, even though some items concern life outside the wards. For transparency, every item is reported. However, we

did not examine why changes appeared outside the ward. If these changes were an effect of the study or an effect of other factors cannot be answered. This aspect could be interesting to include in further studies. The decrease in coercive measures at one point in time might be a temporary alteration that just happened to coincide with the intervention studied but the general trend in the sample data supports the conclusion that the intervention had an impact on the decrease.

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Disclosure statement

Fredrik Edin Renberg is employed as consultant at the clinical site where the study was conducted, but he was not the physician in charge at the wards. Mikael Sandlund has no clinical connection to the site.

Notes on contributors

Fredrik Edin Renberg is consultant in general psychiatry at the hospital in Skellefteå, Sweden. The main fields of his research interest are discrimination and stigma.

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