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Title: The importance of personal recovery and perceived recovery support amongst service users with psychosis

Authors: Regina Skar-Fröding[1], Hanne Kristin Clausen[1,2], Jūratė Šaltytė Benth[3,4], Torleif Ruud[1,3], Mike Slade[5], Kristin Sverdvik Heiervang[1]

[1]Division of Mental Health Services, Akershus University Hospital, Lørenskog, Norway

[2]Norwegian National Advisory Unit on Concurrent Substance Abuse and Mental Health Disorders and Mental Health Division, Innlandet Hospital Trust, Brumunddal, Norway

[3]Institute of Clinical Medicine, Campus Ahus, University of Oslo, Oslo, Norway

[4]Health Services Research Unit, Akershus University Hospital, Lørenskog, Norway

[5]School of Health Sciences, Institute of Mental Health, University of Nottingham, Nottingham, UK

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Highlights:

- This study examined the importance of personal recovery for a large and diverse group of service users with psychosis, and their perceived support from mental health clinicians for personal recovery.
- The majority of the participants rated personal recovery as important, regardless of level of symptoms and functioning.
- Previous experience with Illness Management and Recovery treatment (IMR) was significantly associated with higher support, while high levels of general symptoms and depression were significantly associated with less support.
- The findings have implications for clinical practice, providing empirical evidence that recovery-oriented treatments are relevant for the majority of service users with psychosis in various mental health services.

Previous presentation: no previous presentation

Abstract:

Objective:

More knowledge is needed on whether personal recovery, as defined by the CHIME framework, is considered important for the majority of service users with psychosis. This study examined the importance of personal recovery for a large heterogeneous group of service users with psychosis, and their perceived support from clinicians for personal recovery.

Methods:

This cross-sectional study used baseline data from 321 service users with psychosis from 39 different clinical units across Norway. *The INSPIRE Measure of Staff Support of Personal Recovery* (based on CHIME) was used to examine personal recovery and the perceived support provided for recovery. Bivariate and multiple linear regression models were used to assess variables associated with rated importance and support.

Results:

The majority of the service users rated personal recovery as important, regardless of their level of symptoms and functioning. Previous experience with Illness Management and Recovery treatment (IMR), knowledge about coping with stress and illness, and having a plan for early detection and prevention of relapse were significantly associated with higher support. Higher self-reported depressive symptoms, lower Global Assessment of Functioning Scale -Symptom score, and being male were significantly associated with less support.

Conclusions:

Most service users with psychosis find personal recovery important regardless of level of symptoms and functioning. This has implications for clinical practice, providing empirical evidence that recovery-oriented treatments are relevant for the majority of service users with psychosis in various mental health services.

Introduction

Personal recovery refers to changes in one`s attitude to life and illness with emphasis on hope and the establishment of a meaningful life (1-3). Connectedness, hope, identity, meaning and purpose, and empowerment have been identified as key themes in the personal recovery concept, and provided the acronym CHIME (4). Personal recovery has been contrasted with clinical recovery, where symptom reduction and increased functioning is the main treatment focus (2).

There has been debate over the relationship between personal recovery and the traditional clinical recovery goal of reduced symptomatology and improved functioning (5). This has important clinical implications. Some studies have shown that people with psychosis can participate in working towards personal recovery regardless of their clinical and functional competence (6) while others have shown that service users with more clinical symptoms and lower functioning level prefer clinical recovery goals, such as reducing symptoms and confusion (7). Some have argued that personal recovery is more of a self-realisation concept, in accordance with Maslow's pyramid (8, 9), and that for some service users, more basic needs must be met before self-realisation can occur (10, 11). As CHIME is widely endorsed in the recovery literature (12), more knowledge on the applicability of the framework is

needed. An important step towards this is to clarify whether personal recovery, as conceptualised by the CHIME framework, is considered relevant to the majority of people with psychosis. This can help inform mental health services and the development of recovery-oriented practices. A few studies have used qualitative data to investigate the applicability of the CHIME framework, with results supporting the category structure (13, 14) but also suggesting an expanded conceptualisation of recovery in which experienced difficulties are more prominent (14). However, no studies have examined the applicability of the framework quantitatively.

Support of and focus on personal recovery have become increasingly important aspects of mental health services in many countries (5, 15). Lately, several recovery-oriented interventions, have been developed and implemented in mental health systems internationally (16). For example, Illness Management and Recovery treatment (IMR) (17) aims to improve the ability of individuals with severe mental illness to better manage their illness in areas such as symptomatology, functioning, knowledge, progress towards goals, and hope (18, 19). However, one of the biggest obstacles to the implementation of recovery-oriented practices is the lack of knowledge on how it can be best supported (20). More knowledge on factors associated with perceived support for personal recovery is important for improving treatment and health service development and bridging the gap between the personal recovery vision and clinical practice.

The aims of this cross-sectional study were (1) to examine whether personal recovery as defined by the CHIME framework is considered important by service users with psychosis, (2) how much perceived support for personal recovery service users receive, and (3) predictors of perceived support. The research questions to be answered in the paper are: Is personal recovery important for service users with psychosis? Are there any differences

between service users with different levels of rated importance? How much perceived support for personal recovery do the service users receive? And what are the predictors of perceived support?

Methods

Design

The study had a cross-sectional design with baseline data from the Norwegian research project *A pairwise randomized study on implementation of guidelines and evidence-based treatments of psychoses* (ClinicalTrials NCT03271242). The study was approved by the Regional Committee for Medical and Health Research Ethics (REK Sørøst B 2015/2169), following the principles in the Declaration of Helsinki.

Sample

Inclusion criteria were: mental health service user; aged 16 years or older; diagnosed with psychosis (F20-29) in ICD-10 (21). The only exclusion criterion was that the service users had to be able to understand and answer the questionnaires in Norwegian. Service users (n=4) with missing data were excluded.

Setting

A total of 39 clinical units and hospital departments with outpatient clinics, day units, mobile teams, and inpatient wards participated from six health authorities across Norway, including three university hospitals.

Measures

Service user rated measures:

The INSPIRE Measure of Staff Support for Personal Recovery was used to examine the importance of personal recovery and experienced support from a mental health clinician. The *INSPIRE* is a 27-item self-report questionnaire that measures perceived staff support for personal recovery (22). It consists of two subscales: Support (20 items) and Relationship (7 items). The support items cover five domains: connectedness, hope, identity, meaning and purpose, and empowerment, which were identified through a systematic review and given the acronym CHIME (4). Each of the 20 support items is first rated for whether it is considered important for the participants' recovery (yes/no). If yes, the participants rate the extent of support they experience from their health service provider on that item on a five-point Likert scale (0 = Not at all, 4 = very much). The relationship subscale was not filled out in this study.

The Behavior and Symptom Identification Scale (BASIS-24) is a brief self-report measure of six domains of mental well-being and functioning. The scale has shown good validity and reliability for assessing mental health status from a service user perspective (23, 24).

Two of the six domains were used. The depression/functioning domain was included as a measure of the level of the participants' depressive symptoms. The substance abuse domain was also included and was transformed into a dichotomous variable (substance abuse/no substance abuse). Abuse was defined as a score of 3 (often) or 4 (always) on any of the items

in the domain. Item 22 (Did anyone talk to you about your drinking and drug use?) was excluded as it was considered irrelevant.

Subdomain scores were calculated as described in the BASIS-24 instruction guide (25), providing a score between 0-4 with higher scores indicating more severe problems.

Participants' satisfaction with life was assessed with one item from the *Manchester Short Assessment of Quality of Life (MANSA*) (26). The item "How satisfied are you with your life as a whole?" was rated on a seven-point scale (1 = "couldn't be worse", 7 = "couldn't be better").

Participants also rated six statements about their overall experience with getting help to manage their lives and their illness for the last six months: 1. "I have been well trained in setting goals and working to achieve them"; 2. "I have gained useful knowledge about stress, vulnerability, and social support", 3; "I have gained useful knowledge about coping with stress and illness"; 4. "I have gained useful knowledge on how to use health services better"; 5. "I have gained useful knowledge about the medicines I use"; and 6. "I have prepared a plan for the early detection of any signs of aggravation, and what should be done then". The questions were rated on a five-point scale (1 = strongly disagree, 5 = strongly agree), with an additional option of answering "not relevant". These variables were named 1. Setting goals, 2. Increased knowledge, 3. Coping, 4. Health service use, 5. Medication, and 6. Early detection and prevention of relapse.

The participants also reported if they had participated in IMR groups for the last 6 months (yes/no). This variable was named IMR experience.

Clinician-rated measures:

The Clinical Global Impressions Scale (CGI) was originally developed for use in National Institute of Mental Health (NIMH)-sponsored clinical trials (27). The present study included the CGI-Severity (CGI-S) component, in which clinicians rate the severity of service users' mental illness in the past seven days on a seven-point scale (1 = Normal, not at all ill, 7 = Among the most extremely ill patients) (28).

The Global Assessment of Functioning Scale (GAF) is a standardized assessment of impairment caused by mental factors (29) in which clinicians rate the level of functioning and severity of the service users' symptoms on a scale (1 - 100). Lower scores indicate more severe symptoms and lower levels of functioning. The split version of the scale used in this study has two subscales: Symptom (GAF-S) and Function (GAF-F) (30).

Procedures

Clinicians at participating clinical units recruited service users, performed the clinical ratings and administered the self-report questionnaires to the service users. Recruitment began in June 2016. Eligible service users and newly referred service users assessed to have psychosis were asked to participate, until March 2017. Only participants who gave written informed consent were included.

Analysis

To assess the characteristics associated with number of Important-answers and with total support score bivariate and multiple linear regression models were estimated. First, models with participant characteristics (age, gender, ethnicity, community treatment order, mental health care history), participant-rated measures (depression/function, satisfaction with life, substance abuse), and clinician-rated measures (GAF-S, GAF-F, CGI-S) were estimated. Next, covariates on service users' overall experiences in managing their life and illness (Overall experience 1-6), and whether they had participated in IMR (IMR experience) were added. As participants were recruited to the study by different units, a hierarchical structure could have been present in the data. However, no within-unit correlations were present and hence no adjustment was needed. Correlation analysis did not identify any multicollinearity issues among covariates. Residual diagnostics did not show any significant deviations from linear regression model assumptions. Both bivariate and multiple models were estimated for cases with no missing values on covariates. Results with p-values below 0.05 were considered statistically significant. The analyses were performed using SPSS v. 25.

Imputation of the GAF and the MANSA scales was performed on cases with fewer than 50% missing values as follows. The empirical distribution for each item in the scale was determined. A random number was drawn from that distribution and used to replace the missing value. The process was repeated until all missing values were imputed.

Results

Sample characteristics

The characteristics of the 321 participants are shown in Table 1.

Importance of personal recovery

The importance rating for the 20 INSPIRE items ranged from 66 to 91%, as shown in Table 2. Ten (3%) participants answered No (Not important) on all 20 items, and 167 (52%) answered Yes (Important) for between 17 and 20 items. Figure 1 provides a further detailed description of number of "Important" answers.

Differences between service users with different levels of rated importance

Multiple linear regression model explained 4.8% of the total variation in the number of "Important" answers. When covariates on service users' overall experience with managing their life and illness for the last 6 months (Overall experience 1-6) and information on participation in IMR groups for the last 6 months (IMR experience) were included, the multiple linear regression model explained 8.1% of the total variation (Table 3). Higher scores on the depression/function domain and lower scores on *"I have gained useful knowledge about the medicines I use*" (5. Medication) were associated with fewer "Important" answers in the bivariate models, but no significant associations were found in the multiple model.

Support for personal recovery

The overall level of experienced support per item ranged from 2.27-2.83 (Table 2).

The multiple linear regression model explained 14.8% of the total variation in experienced support. When covariates on service users' overall experience with managing their life and illness for the last 6 months (Overall experience 1-6) and information on participation in IMR groups for the last 6 months (IMR experience) the multiple linear regression model explained 31.1% of the total variation in experienced support (Table 4). In the multiple

model, lower GAF-S score, higher depression/functioning score, and being male were significantly associated with lower levels of perceived support among the participants. Also, higher scores on *"I have gained useful knowledge about coping with stress and illness"* (3. Coping) *and "I have prepared a plan for the early detection of any signs of aggravation, and what should be done then"* (6. Early detection and prevention of relapse) and having participated in IMR groups for the last 6 months (IMR experience) were significantly associated with higher perceived support.

Discussion

This study shows that the majority of service users with psychosis consider personal recovery, as operationalized using the CHIME framework, to be important. There were no differences between service users rating personal recovery as less important and those rating it as more important. Overall, the service users experienced only moderate support for personal recovery. Higher self-reported depressive symptoms, lower GAF-S score and being male were significantly associated with less perceived support. Having participated in IMR groups, having gained knowledge about coping with stress and illness and having a plan for early detection and prevention of relapse for the last 6 months were significantly associated with higher support.

Our main finding in this study is that the great majority of a large heterogeneous group of service users with psychosis across several clinical units report that personal recovery is important for them regardless of age, ethnicity, symptomatology, functioning, community treatment order status and time in mental health care. This has implications for clinical

practice, providing empirical evidence that recovery-oriented treatments are relevant for the majority of service users with psychosis in various mental health services.

However, although the great majority of participants reported personal recovery to be of high importance, they only experienced a moderate degree of personal recovery support from their health service provider. Several factors can influence the level of experienced support for recovery, not in the least how recovery-oriented the different clinicians and the different mental health units are. Our findings show that previous experience with IMR and related themes, such as knowledge about coping with stress and illness and having a plan for early detection and prevention of relapse, were significantly associated with higher support. This suggests that recovery-oriented treatments such as IMR and related themes may be effective in making people feel supported in their process of personal recovery, a result in line with a recent meta-analysis showing greater improvement in personal recovery outcomes when service users are involved in recovery-oriented mental health treatment versus usual care or other types of treatment (31).

Further, we found that higher self-reported depressive symptoms, lower GAF-S score, and being male were significantly associated with less perceived support. This is of clinical importance. That is, it is important not to be blinded by high levels of general symptoms or depression, because these service users still think personal recovery is important. Although we cannot conclude about the causality among these associations, our results still points to the importance of providing support for personal recovery, also among service users with high levels of general symptoms and depression. Future research should examine how patterns of importance ratings change over time and how perceptions of support are influenced by treatment.

Previous research has shown that affective symptoms seem to be more closely linked to personal recovery and related themes, such as quality of life, than psychotic symptoms (5, 32, 33). Our finding that higher level of self-reported depression was related to less perceived support, supports the important notion that there is an association between affective symptoms and personal recovery among service users with psychosis.

A major strength of this study is the broad group of participants with psychosis as well as the many different units that participated, enabling us to gain information that can be generalised to a range of mental health services for service users with psychosis. A limitation of the study is the lack of data on how representative our group of participants is, compared with the overall Norwegian psychosis population. Since the participants were not randomly selected, they may not be accurately representative of the Norwegian psychosis population. Another important limitation is the cross-sectional nature of this study which prevents conclusions regarding the causality among the associations.

Conclusions

This study shows that the great majority of a large heterogeneous group of service users with psychosis across several clinical units report that personal recovery is important for them regardless of age, ethnicity, symptomatology, functioning, community treatment order status, and time in mental health care. This has implications for clinical practice, providing empirical evidence that recovery-oriented treatments are relevant for the majority of service users with psychosis in various mental health services. Recovery-oriented treatments such as IMR, and related themes such as help for coping with stress and illness and having a plan for early detection and prevention of relapse seem to make people with psychosis feel more supported by workers in their personal recovery process. Specific attention should be given

to service users with high levels of general symptoms and depression, because these service users experience less support for personal recovery, even though personal recovery is equally important for them.

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Figur 1. Descriptive statistics for number of "Important" answers (N=321)

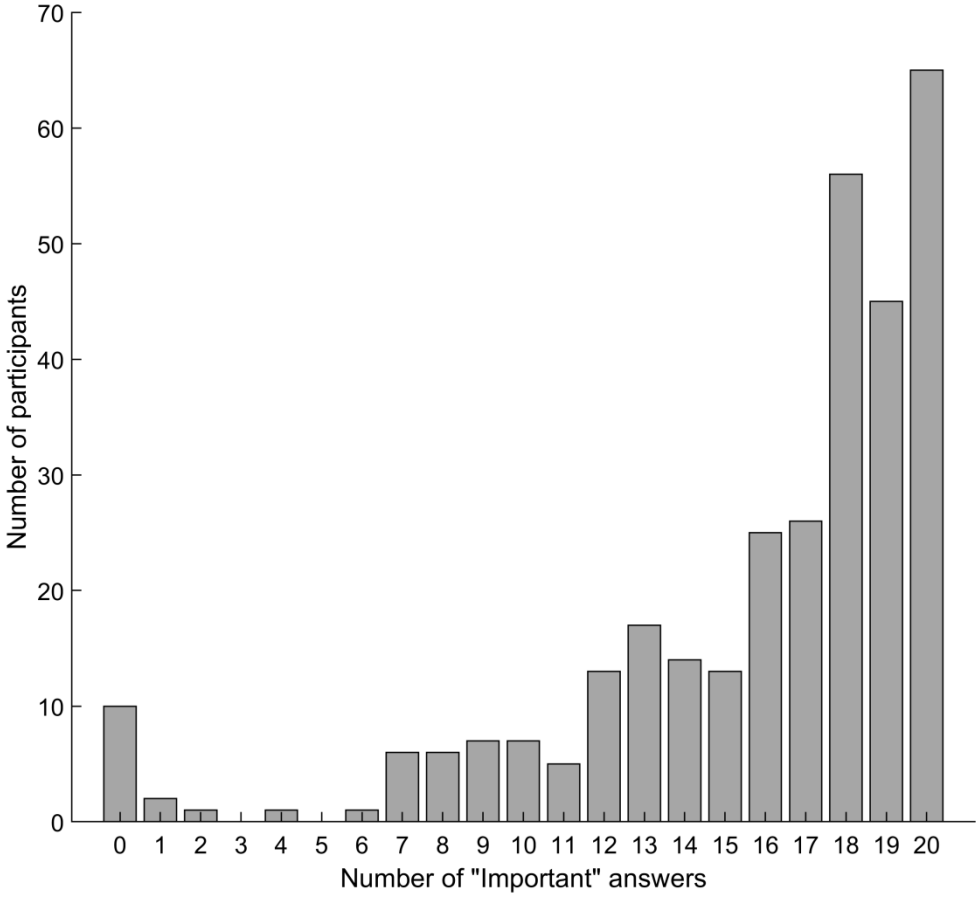

Table 1. Sociodemographic characteristics of participants (N=321)

Characteristics	N	%	M	SD	Min-max	Missing (n)
Gender						1
Female	133	41				
Ethnicity						5
Norwegian	277	88				
Other	39	12				
Age	310	97	40	12.7	16–77	11
Diagnosis						25
Schizophrenia	158	53				
Schizoaffective disorder	59	20				
Other	79	27				
GAF symptom	321	100	53	13.0	26–90	
GAF function	321	100	51	11.3	20–85	
Community treatment order						7
Yes	42	13				
Mental health care history						14
<6 months	20	7				
6-23 months	28	9				
2-5 years	50	16				
6-10 years	64	21				
>10 years	145	47				
Education completed						11
Not completed primary school	9	3				
Primary school	96	31				
Upper secondary school	81	26				
Vocational education	53	17				
Higher education	62	20				
Other	9	3				

Table 2. Item level ratings of the INSPIRE Measure of Staff Support of Personal Recovery of participants (N=321)

An important part of my recovery is……	Not important		Important		Perceived support	
	N	%	N	%	M	SD
Connectedness						
S1 Feeling supported by other people	37	11	284	89	2.83	0.85
S2 Having positive relationships with other people	30	9	290	91	2.73	0.89
S3 Having support from people who use services	98	31	217	69	2.61	0.92
S4 Feeling part of my community	74	23	246	77	2.62	0.99
Hope						
S5 Feeling hopeful of my future	58	18	259	82	2.61	1.02
S6 Believing I can recover	40	12	280	88	2.79	0.96
S7 Feeling motivated to make changes	68	21	250	79	2.62	1.02
S8 Having hopes and dreams for the future	51	16	268	84	2.62	1.06
Identity						
S9 Feeling I can deal with stigma	91	30	214	70	2.27	1.12
S10 Feeling good about myself	70	22	247	78	2.59	0.98
S11 Having my spiritual beliefs respected	99	32	215	68	2.61	0.96
S12 Having my ethnic/cultural/racial identity respected	105	34	207	66	2.71	1.11
Meaning and purpose						
S13 Understanding my mental health experiences	63	20	251	80	2.73	0.10
S14 Doing things that mean something to me	34	11	285	89	2.74	0.91
S15 Rebuilding my life after difficult experiences	52	16	264	84	2.78	0.98
S16 Having a good quality of life	40	13	278	87	2.69	0.99
Empowerment						
S17 Feeling in control of my life	55	17	262	83	2.70	1.03
S18 Being able to manage my mental health	37	12	281	88	2.80	0.94
S19 Trying new things	104	32	216	68	2.53	0.10
S20 Building on my strengths	46	14	271	86	2.61	0.98

Table 3. Results of linear regression model for number of "Important" answers (N=275)

Variables	Bivariate models			Multiple models		
	Regression coefficient	95% CI	p	Regression coefficient	95% CI	p
GAF-Symptom	-0.01	-0.06 to 0.03	.515	-0.02	-0.09 to 0.04	.471
GAF-Function	-0.00	-0.05 to 0.05	.862	-0.01	-0.08 to 0.06	.799
CGI-Severity (CGI-S)	-0.16	-0.55 to 0.24	.436	-0.13	-0.64 to 0.38	.622
Depression/functioning	-0.62	-1.22 to -0.03	.040	-0.56	-1.34 to 0.23	.165
Satisfaction with life	0.29	-0.12 to 0.69	.161	-0.14	-0.64 to 0.37	.596
Age	0.02	-0.03 to 0.06	.410	0.03	-0.03 to 0.08	.368
Female (reference: male)	1.00	-0.12 to 2.13	.081	0.71	-0.51 to 1.93	.252
Ethnicity (reference: Norwegian)	-0.10	-1.84 to 1.65	.915	-0.42	-2.29 to 1.45	.660
CTO (reference: no)	0.84	-0.78 to 2.46	.307	1.00	-0.74 to 2.74	.259
Mental health care history (reference: >10 years)						
<6 months	-0.29	-2.67 to 2.09	.812	0.49	-2.05 to 3.03	.705
6-23 months	0.50	-1.59 to 2.59	.637	1.26	-0.97 to 3.49	.267
2-5 years	1.09	-0.49 to 2.67	.177	1.42	-0.35 to 3.19	.116
6-10 years	-0.83	-2.33 to 0.66	.273	-0.61	-2.28 to 1.05	.469
Substance abuse (reference: no)	-0.84	-2.46 to 0.78	.308	-0.24	-2.01 to 1.53	.789
Overall experience						
1. Setting goals	0.51	-0.01 to 1.04	.054	0.34	-0.34 to 1.02	.325
2. Increased knowledge	0.33	-0.15 to 0.81	.173	0.11	-0.78 to 1.00	.806
3. Coping	0.30	-0.22 to 0.81	.255	-0.24	-1.13 to 0.66	.216
4. Health service use	0.06	-0.46 to 0.57	.831	-0.42	-1.10 to 0.25	.057
5. Medication	0.60	0.09–1.11	.021	0.58	-0.02 to 1.17	.253
6. Early detection and prevention of relapse	0.38	-0.07 to 0.83	.100	0.33	-0.24 to 0.90	.617
IMR experience (reference: no)	-0.53	-1.76 to 0.70	.400	-0.35	-1.73 to 1.03	.617

Table 4. Results of linear regression model for perceived support sum score (N=264)

Variables	Bivariate models			Multiple models		
	Regression coefficient	95% CI	p	Regression coefficient	95% CI	p
GAF-Symptom	0.19	0.03–0.35	.021	0.22	0.01–0.43	.039
GAF-Function	0.23	0.04–0.42	.017	-0.06	-0.29 to 0.17	.617
GCI-Severity (CGI-S)	-0.93	-2.41 to 0.55	.218	0.88	-0.77 to 2.52	.295
Depression/functioning	-4.82	-7.01 to -2.64	<.001	-3.79	-6.37 to -1.21	.004
Satisfaction with life	2.75	1.27–4.22	<.001	-0.21	-1.85 to 1.43	.800
Age	0.12	-0.05 to 0.28	.180	0.07	-0.11 to 0.24	.473
Female (reference: male)	6.86	2.69–11.03	.001	5.15	1.18–9.11	.011
Ethnicity (reference: Norwegian)	2.75	-3.78 to 9.28	.408	2.87	-3.23 to 8.96	.355
CTO (reference: no)	0.65	-5.35 to 6.65	.830	1.57	-4.03 to 7.17	.582
Mental health care history (reference: >10 years)						
<6 months	-5.35	-14.40 to 3.70	.245	-3.28	-11.62 to 5.05	.438
6-23 months	-6.04	-13.91 to 1.84	.133	-2.99	-10.29 to 4.30	.420
2-5 years	-3.34	-9.20 to 2.53	.263	-3.06	-8.77 to 2.66	.293
6-10 years	-1.07	-6.75 to 4.62	.712	0.21	-5.48 to 5.52	.994
Substance abuse (reference: no)	-3.19	-9.17 to 2.80	.295	4.33	-1.39 to 10.05	.137
Overall experience						
1. Setting goals	5.67	3.81–7.54	<.001	1.71	-0.51 to 3.93	.131
2. Increased knowledge	4.85	3.17–6.52	<.001	0.06	-2.82 to 2.93	.969
3. Coping	6.33	4.58–8.08	<.001	3.91	1.03–6.80	.008
4. Health service use	4.39	2.56–6.22	<.001	0.86	-1.36 to 3.07	.446
5. Medication	3.62	1.74–5.49	<.001	0.55	-1.37 to 2.47	.572
6. Early detection and prevention of relapse	4.55	2.93–6.17	<.001	2.13	0.26–4.00	.025
IMR experience (reference: no)	0.09	-4.55 to 4.72	.971	4.62	0.08–9.16	.046