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ARTICLE

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Evaluation of health services and treatment alliance among extensively hospitalized patients due to severe self-harm – results from the Extreme Challenges project

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ABSTRACT

Background: Extensive psychiatric hospitalization due to repeated severe self-harm (SH), is a poorly researched area, but a challenge within health services (HS). Recent studies have demonstrated high levels of involuntary treatment among patients with severe personality disorder (PD) and complex comorbidity. Keeping focus on extensively hospitalized SH patients, this study aimed to investigate patients' and clinicians' evaluation of HS and treatment alliance.

Method: A cross-sectional study with an inpatient sample (age >18years) with frequent (>5) or long (>4weeks) psychiatric hospital admissions last year due to SH or SA recruited from 12 hospitals across health regions ($N = 42$). Evaluation included patient and clinician report.

Results: A minority of the patients (14%) were satisfied with HS before the current admission, 45% (patients) and 20% (clinicians) found the current admission helpful, and 46% (patients) and 14% (clinicians) worried about discharge. Treatment complaints were received in 38% of the cases. Outpatient mental HS were available after discharge for 68% and a majority of clinicians indicated satisfactory contact across HS. More intensive or specialized formats were unusual (structured outpatient treatment 35%, day treatment 21%, ambulatory services 32%, planned inpatient services 31%). Mutual problem understanding, aims, and confidence in therapists during the hospital stay were limited (patient-rated satisfactory mutual problem understanding: 39%, aims of stay: 50%, confidence: 50%). Patient and therapist alliance-ratings were in concordance for the majority.




Conclusion: The study highlights poor HS satisfaction, poor patient–therapist coherence, limited treatment alliance and limited follow-up in structured treatments addressing SH or intermediary supportive ambulatory/day/inpatient services.

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Introduction

Self-harming behaviors, defined as intentional self-injury or self-poisoning, irrespective of motive or the extent of suicidal intent [1] are most common among adolescents and young adults [2]. Although the initial severity of these behaviors may be mild, they are significant predictors of psychopathology, suicide attempts, and increased mortality [3–8]. Self-harm (SH) is associated with a 30-fold risk of suicide [9] and an increased risk for long-lasting and costly patterns of health service use, often for psychiatric complaints [10]. This study is part of a larger research project (Extreme Challenges) which targets a poorly described, but severe subgroup of SH patients with extensive hospitalization [11]. This study focuses on experiences of health care and treatment alliance as evaluated by inpatients and clinicians.

The target situation is highly challenging for both patients and health services (HS), not least the ethical, therapeutic, and personal aspects of enduring high-risk situations. Extreme situations with ongoing health and suicide threat represent substantial clinical dilemmas where chronic severity may override, otherwise recommended, treatment strategies. These patients are few, but may take up a disproportionate percentage of the acute psychiatric capacity. In a British multicentre study 0.6% of the SH patients accounted for 10% of the SH attendances in the HS during a 4-year period [12]. A preliminary screening investigation involving psychiatric adult inpatient institutions across all health regions in Norway, reported 2 cases per department as a mean yearly occurrence of severe SH and extensive hospitalization [13]. Although the severe SH situations were infrequent, their magnitude in terms of health care resources and severity of condition was striking. Medical sequelae and mortality due to SH/suicide was notable.

Major challenges within and across HS were described in the study of Holth et al. [13], where collaboration problems were reported in 29% of the cases. These included unclear involvement and responsibility across services, disagreements on treatment requirements, and an experience that the patients were either not suited for more specialized SH treatment or that such treatment was unavailable. Problems of discontinuity of care for psychiatric patients have also been emphasized in a large-scale, European study [14], which demonstrated fragmented and lacking cooperation across service levels as well as along the life course.

Current evidence on SH treatment is represented in a large body of research, mainly based on the milder, and more common conditions; self-harming behaviors with no intent of suicide (non-suicidal self-injury [15–17]). In severe cases, however, SH can involve serious mutilation and be life threatening, and suicidal intent may be clearly present or hard to discern. As few studies include the most severe SH patients, recommended SH treatment may have limited generalizability.

Inpatients with recurring and severe SH are often engaged in restrictive and involuntary treatment regimes. Establishing satisfactory collaborative processes thus represents significant therapeutic challenges. Moreover, it is to be expected that troubled interpersonal styles and attitudes among persons

with personality disorders (PDs) generally complicate a working alliance [18]. In particular, poorly functioning patients tend to elicit stronger negative reactions in health practitioners [19]. Working alliance is a concept developed in the context of psychotherapy and is often defined as the tightly knit threefold web of mutuality between the patient and therapist concerning treatment goals, the main tasks of therapy, and a personal bond [20]. Together, these elements form a foundation considered essential for positive outcomes – a good alliance is generally a robust predictor of positive outcome in psychotherapy [21] and a key element in treatment for SH [22]. Significant associations between alliance and SH have been established, with good alliance ratings proving to have helpful impact on the patient's suicidality [23]. Although the targeted inpatient situation expands the framework of traditional psychotherapy, the elementary mechanisms of working alliance may also generalize to such treatment formats and collaborative processes.

The impact of repeated, negative treatment experiences, re-hospitalizations, or lack of collaboration within and across HS should not be underestimated. From a patient perspective, a sense of failure or hopelessness can clearly be accentuated [24,25]. From the perspective of staff, a risk of developing negatively stigmatizing attitudes [26] or resignation toward patients with severe SH has been highlighted [27].

The Extreme Challenges research project

Extreme Challenges is a cross-regional research project involving psychiatric hospitals situated in all four health regions of Norway. It targets an extreme subgroup of patients with severe self-harming behaviors and current, extensive psychiatric hospitalization. It was developed as a response to repeated referrals to a national advisory unit for PD from clinicians in psychiatric hospitals concerning complex, high-risk clinical situations [11]. The project includes several independent studies focusing on the status of mental health disorder and health service application in the target population. The aim of this study is to investigate patients' and clinicians' evaluation of the provided health care and main aspects of alliance as perceived during the hospital stay.

Material and methods

The study design was cross sectional, developed in cooperation with a national project group (clinicians, researchers, patient- and public involvement representatives).

Participating hospitals represented adult psychiatry inpatient units (age 18–65 years). Inpatient adult mental health services (HS) within all health trusts in Norway were invited to participate (Supplementary Table 1). Medical/surgical departments and specialized units for substance use/addiction, eating disorders, developmental disorders, or intellectual disability were excluded.

Eligible patients included all inpatients with >5 psychiatric hospital stays the last 12 months and/or >4 weeks duration of hospital stay, due to severe SH or the risk thereof. This definition was developed by consensus within the national

project group and was in accordance with the preceding screening investigation [13].

Invitations to participate and project information were conveyed by members of the national project group and included e-mail correspondence, meetings at local hospitals in all regions, and national conference presentations. The participating hospitals identified and invited eligible patients and upon patients' informed consent, administered assessments.

The data collection period was 2019–2021. The study sample consisted of 42 patients from 12 hospitals representing all health regions of Norway (Supplementary Table 1).

The assessments covered all aspects of the project (Supplementary Tables 2–4). Systematic assessment training was provided by experts in the national project group and included: (1) All participating clinicians were invited to locally arranged workshops on diagnostic interviews and assessments, participation was optional, (2) To ensure availability of training, relevant information was shared on a project website in Norwegian language throughout the investigation period.

Assessment of the target situation included: (a) Patient self-report and clinical interview on SH/suicide attempts (SH/SA) occurrence, frequency, and development from first time as presented in a former publication (LPC, [11,28]). (b) Patient report and clinical interview on former inpatient and outpatient treatments, age first time to be presented in a separate publication (current status is presented in Table 1).

Background information on age, gender, current living situation, allowance/pension were collected by the validated five-item self-report: EuroQuoL 3L – EQ-5D-3L [29], rating health-related quality of life on a 1–3 scale, scores ≥ 2 indicate some/considerable problems (1: Movement, 2: Personal management, 3: Social/occupational activity, 4: Pain, 5: Anxiety/Depression) and a visual analogue scale (VAS), ranging health state/burden of disease from worst to best possible (scores 0–100). Mean VAS in general population studies

range 80–89 [30,31]. Diagnoses were evaluated by clinicians using the M.I.N.I. International Neuropsychiatric Interview (MINI, [32] for symptom disorders and the Structured Clinical Interview for DSM-5 Personality Disorders (SCID-5-PD, [33]). We present the total number of symptom disorders and total number of SCID-5-PD criteria as background information. The additionally applied Levels of Personality Functioning-Brief Form (LPFS-BF 2.0) [34] is a twelve-item patient self-report of DSM-5 Level of Personality Functioning Scale (Alternative Model of Personality Disorders), scored on a 0–3 scale ('Very false, Often False', 'Often true', 'Very True') [34,35]. LPFS-BF sum-score >15 exceeds population norms (1–4 scale) [36]. Sociodemographic and clinical status is presented in Table 1. Further elaboration is presented in a former publication [11].

Information on HS and collaborations was collected during the admission. Clinician and patient report on collaboration was administered independently.

Enquiry about patients' and clinicians' satisfaction with HS

Items were designed for the study and rated on a 0–2 scale (0 = no, 1 = partly, 2 = absolutely). Evaluation of HS before current admission was collected by patient report. Evaluation of the current admission, satisfaction with plans for discharge and follow-up, and communication/collaboration outside the hospital (HS and family/next of kin) was rated by both patient and clinician. Other external involvement was rated by clinicians and included enquiry about higher levels within the hospital, ethics committee, involvement of other hospitals, and official complaints (Table 2).

Enquiry about experiences of alliance and communication during the current hospital stay Items were designed for the study with patients' and clinicians' evaluation of alliance and communication during the hospital admission rated on a 0–2 score range (0=no, 1=partly, 2=absolutely, Table 3). The experience of mutuality (agreement) concerning understanding patients' problems, aims of hospital stay, perceived communication and agreement between primary contacts and main therapists, and the patients' (perceived) confidence and alliance to therapists and primary contacts was rated by both patients and clinicians. Experienced mutuality regarding the applied treatment during the hospital stay, follow-up after discharge and communication with family/next of kin was rated by clinicians.

Ethics

Approval was given by the Norwegian Regional Ethics Committee (REK; 2018/1124/REK Sør-Øst). Data collection procedures were approved by the local Data Protection Officer at each contributing hospital. Extreme Challenges has pre-registration in Clinical Trials (NCT03768674).

Statistics

Analyses were performed using software IBM SPSS version 28 (IBM SPSS Statistics, Armonk, NY). Statistical comparison of

Table 1. Background information.

	%	Mean (SD) (median)
SH/SA		
Former SH: Number of incidents >100	69	
Former SA: Number of incidents >5	68	
Daily SH and/or suicidal ideation	79	
Psychiatric hospital admissions		
Psychiatric hospital admissions last 5 years (number)		31(25) (25)
Longest hospital stay (number of weeks)		74(63) (49)
Sociodemographic status		
Female gender	95	
Age		31(9)
Living alone	63	
Disability pension/work allowance	82	
EQ5D-3-L, score ≥ 2:		
Movement problems	32	
Personal management	51	
Social/occupational activity	88	
Pain	66	
Anxiety/depression	100	
VAS		37(22)
Mental health status		
LPFS-BF		17.4(7.3)
SCID-5-PD criteria (number)		14.6(7.0)
Other mental health disorders (number)		4(2.4)

Table 2. Evaluation of health services, treatment, and collaborations.

		No	Partly	Absolutely	
		%	%	%	
Health care 6-month period before current admission					
Patient-report	I received the health care I needed	31	55	14	
	Community (primary service level) services were important	52	14	33	
	Specialist mental health center was a part of my health care	21	26	52	
	If partly or absolutely, was it helpful?	13	60	27	
	I received treatment at other hospital departments (medical/surgical)	33	33	35	
	If partly or absolutely, did you receive good health care?	0	41	59	
	My GP was a support for me	41	17	43	
Current admission to psychiatric hospital					
Patient-report	The current admission is helpful for my problems ^a	14	41	45	
Clinician report	The current admission is helpful for the patient's problems ^a	9	71	20	
	The hospital has enough professional competence	0	42	58	
	The hospital has enough resources	0	50	50	
Discharge and follow-up					
Patient report	I am worried about the discharge ^b	17	37	46	
	I wish to plan for follow-up after discharge	5	37	59	
	Main therapist talks to me about this	29	26	45	
	Primary contacts talk to me about this	31	46	23	
	I think I will be satisfied with follow-up after discharge	23	48	30	
Clinician report	I am worried about the discharge ^b	31	54	14	
	I think the patient will collaborate on follow-up after discharge	3	60	37	
	I am worried about sufficient follow-up after discharge	21	53	27	
	If partly/absolutely worried:	58	33	8	
	Insufficient GP	44	39	17	
	Insufficient community health services				
	Insufficient specialist mental health services	25	50	25	
	Insufficient collaboration between health service levels	25	46	29	
	Communication/collaboration outside the hospital				
	Patient report	Does your family/next of kin receive sufficient information from the hospital	27	44	29
I wish contact between the hospital and my family/next of kin		38	26	36	
Is the hospital's collaboration with your GP sufficient?		61	27	12	
I wish collaboration between the hospital and my GP		7	21	71	
Has the hospital communicated with other primary health services		40	33	28	
I wish collaboration with hospital and primary health services		20	15	66	
Will you receive treatment in SMHS* after discharge		17	17	67	
I wish collaboration with hospital and mental health service		10	17	73	
Clinician report		There is established contact with primary health services	14	0	86
		Relevant primary health services are available	14	37	49
	An external therapist within SMHS is involved	21	0	79	
	Outpatient SMHS are available	12	21	68	
	Day treatment within SMHS is available	71	9	21	
	Structured therapy programs available in SMHS (DBT, MBT, SFT etc.)	33	30	36	
	Ambulatory mental health services are available in SMHS	35	32	32	
	Planned, brief admissions (inpatient SMHS) are available	34	34	31	
External involvement					
Clinician report	The case has been discussed on a higher level within the hospital			74	
	The clinical ethics committee has been involved			6	
	Referral for second opinion patient assessment by other hospital			18	
	There have been official complaints on treatment received			38	

Table 2 includes reports from both clinician and patient and demonstrates ratings of health care before and during current admission, as well as considerations of discharge, follow-up, and contact with other services. *Specialist mental health services is indicated by the abbreviation SMHS. The directly compared clinician and patient ratings are marked with ^a and ^b. Differences were significant at levels of $p < 0.05$.

clinicians' and patients' ratings were performed by one-sample T-tests defining in both cases the test value as the mean score of the patient-ratings, exact p values are presented together with estimations of Cohens d .

Results

Table 1 demonstrates background information with clinical and sociodemographic status.

Patients' and clinicians' satisfaction with health services

Experiences of HS six months prior to admission were rated by the patient self-report (Table 2). Fourteen percent reported sufficient health care, 55% partly and 31% insufficient. Fifty-two percent reported that community HS were unimportant, and a corresponding proportion considered specialist mental HS important. A large proportion who had received treatment at other hospital departments (medical/surgical), reported good health care within these departments (59%).

Table 3. Experiences of alliance and communication.

		No	Partly	Absolutely
		%	%	%
Mutuality of problem understanding, aims of hospital stay and confidence				
Patient report	Main therapist understands my problems ^a	12	49	39
	Primary contacts understand my problems	13	58	30
	Main therapist and I agree on the aim of my hospital stay ^b	24	26	50
	Primary contacts and I agree on the aim of my hospital stay	17	36	48
	Mean sum % patient rated experience of mutuality	16	42	42
Clinician report	Main therapist and patient agree about what is the patient's problem ^a	8	50	42
	Primary contacts and patient agree about what is the patient's problem	6	53	42
	Main therapist and patient agree on the aim of the hospital stay ^b	14	31	56
	Primary contacts and patient agree on the aim of the hospital stay	6	42	53
	Mean sum % clinician rated experience of mutuality	8	44	48
Patient report	My main therapist and primary contacts communicate about my situation	5	33	63
	They seem to agree about my problems	11	37	53
	They seem to agree on the aim of my hospital stay	8	23	69
	They seem to agree on your needs for follow-up after discharge from hospital	3	39	59
	Mean sum % patient rated experience of team mutuality	7	33	61
Clinician report	Main therapist and primary contacts communicate about the patient	0	6	94
	Main therapist and primary contacts agree on patient's main problems	0	9	91
	Main therapist and primary contacts agree on the aim of the patient's stay	3	17	80
	Main therapist and primary contacts agree on the treatment applied	3	26	71
	Mean sum % clinician rated experience of team mutuality	2	15	84
Patient report	I have confidence in my main therapist at the hospital ^c	17	33	50
	I have confidence in my primary contacts (milieu therapists)	12	46	42
	Mean sum % patient rated experience of confidence	15	40	46
Clinician report	Main therapist experiences a confident alliance to the patient ^c	3	47	50
	Primary contacts have a confident alliance to the patient	3	47	50
	Mean sum % clinician rated experience of confidence	3	47	50
Mutuality on treatment, follow-up and communication with family/next of kin				
Clinician report	Main therapist and patient agree on the treatment which is applied	17	44	39
	Main therapist and patient agree on follow-up plan	14	31	56
	Primary contacts and patient agree on follow-up plan	17	31	53
	Mean sum % clinician experience of mutuality on treatment & follow-up	16	35	49
	Hospital and primary services agree about the patient's main problems	3	28	69
	Hospital and primary services agree on the patient's needs for follow-up	6	34	59
	Hospital vs. relevant mental health services agree on main problems	9	37	54
	Hospital vs. relevant mental health services agree on needs for follow-up	9	37	54
	Mean sum % clinician rated mutuality with external collaborators	7	34	59
Clinician-report	Hospital and family/next of kin agree about the patient's main problems	9	41	50
	Hospital and family/next of kin agree on the patient's needs for follow-up	16	41	44
	Mean sum % clinician experience of agreement with family/next of kin	13	41	47

Table 3 demonstrates mutuality of agreement between patients and therapists, within teams and across health service levels as well as confidence to hospital therapists. The table includes perspectives from both clinician and patient. The directly compared clinician and patient ratings are marked with ^{a,b} and ^c. Differences were not significant ($p > 0.05$).

Forty-three percent rated their general practitioner [37] as clearly supportive, 43% not supportive. Thirty-five percent did not contact emergency crises services if they had a difficult time while 27% reported use of emergency crises services in such situations.

The current admission was rated by both clinicians and patients (Table 2, Figure 1). Clinician and patient ratings of the item 'The current admission is helpful for my problems' differed significantly ($p = 0.036$, $d = -0.37$). Among patients, 45% experienced the admission as clearly helpful. Among clinicians, 20% experienced the current admission as clearly helpful for the patient. Patients' and clinicians' ratings were coherent in 40% of the cases (unhelpful 3%, partly helpful 29%, clearly helpful 9%). In 37% of the cases clinicians rated partly helpful and patients rated clearly helpful (other disagreements ranged 3–6%). No clinicians reported that the hospital lacked competence or resources, but 42–50% indicated "partly sufficient" competence and resources, respectively.

Considerations of discharge and follow-up were rated by both patients and clinicians (Table 2). Among patients, the largest proportion reported clear concern about discharge (46%) while 17% were not worried. Most patients wished to

plan for follow-up after discharge (59%). Their experience of communication with hospital therapists on plans for follow-up were mixed; 29–31% experienced no communication on this topic. Their expectations of satisfaction with the resulting follow-up were also mixed, 23% did not expect to be satisfied, 30% expected clear satisfaction. Among clinicians, 31% were not worried about discharge, only 14% indicated clear concern, and the majority (54%) indicated 'partly' concerned. Clinicians were most concerned about adequate health care within specialist mental HS (25%) and collaboration between service levels (29%). Most clinicians (60%) expected that the patient would 'partly' collaborate on follow-up plans after discharge.

Differences between clinician and patient ratings of the item 'I am worried about discharge' bordered on significance ($p = 0.058$, $d = -0.33$) (Figure 1). Patients' and clinicians' ratings were coherent in 35% of the cases (not worried 6%, partly worried 21%, clearly worried 9%). Disagreements were evident where clinicians rated 'not worried', and patients rated 'partly worried' (18%), and where clinicians rated 'partly worried' and patients rated 'clearly worried' (24%). Other disagreements accounted for 6% each.

Patient- and clinician-report on current admission and worry about discharge

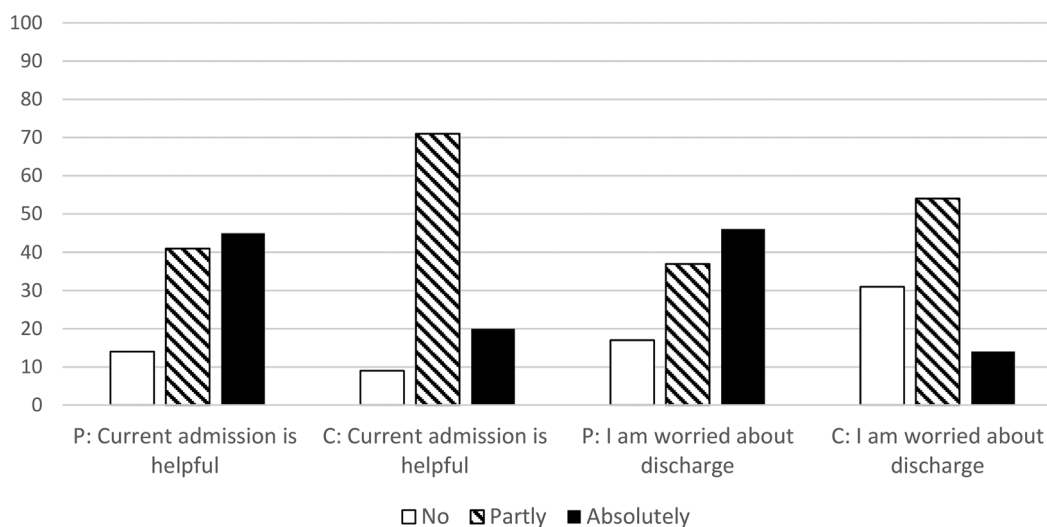


Figure 1. Demonstrates patient- and clinician-rated experiences of how the current admission is helpful for the patients' and to which extent there is concern about discharge from the current hospital admission.

Patient-reported experience of communication/contact between the hospital and with family/next of kin indicated that the majority were only partly satisfied (44%, Table 2). Among patients who clearly wished communication/contact (36%), 33% reported dissatisfaction, 33% partly satisfied, and 33% clearly satisfied. Among patients who did not wish such contact (38%) 20% reported unsatisfactory communication/contact, 53% were partly satisfied, and 27% clearly satisfied.

Most patients wished collaboration with their GP (71%) but did not experience that the hospital communicated with their GP (61%). Correspondingly, few (28%) experienced ongoing collaboration between the hospital and primary HS, although 66% indicated that this was clearly wanted (Table 2). Clinicians contrastingly, reported that contact within primary HS was established for 86% and a total of 49% would have access to relevant primary HS on discharge from the current hospital stay. Among patients who clearly wished primary HS collaboration, clinicians reported contact with primary HS in 96% and access to relevant primary HS on discharge from the current hospital stay for 55%.

Most patients indicated motivation for collaboration between the hospital and specialist mental HS outside the hospital (73%) and experienced that such collaboration was established (67%). Clinicians correspondingly, confirmed contact with different specialist mental HS, most often an external therapist (79%) and on discharge, clear availability of outpatient specialist mental HS (68%). Clinicians indicated that day treatment formats were available for 21% and not available for 71%, relevant structured therapy programs were available for 36%, and not available for 33%, and planned inpatient admissions and ambulatory mental HS were available for 31–32% and not available for 34–35% (respectively). Among the patients who clearly wished specialist HS collaboration, clinicians reported ongoing contact with an external therapist in 87%, and on discharge, availability of other outpatient treatment for 74% (not available 4%), day treatment

13% (not available 83%), ambulatory teams 22% (not available 39%), planned inpatient services 42% (not available 25%) and structured therapy programs 36% (not available 36%).

A majority of cases had been discussed on a higher administrative level within the hospital (Table 2). In 38%, official complaints on the treatment received were reported. The clinical ethics committee was seldom involved. A minority had received a second opinion assessment at a different hospital.

Experiences of alliance and communication during the current hospital stay

Overall, reports from both patients and clinicians including consideration of family/next of kin revealed that less than half the sample considered these aspects clearly satisfactory. Answers to each item are presented as proportions in Table 3.

Pooling patient-rated patient-therapist agreement on problems and aims of stay, 16% reported a lack of agreement, 42% 'partly', and 42% 'absolutely'. Greater mutuality was indicated between therapists/primary contacts (team score 'absolutely': mean sum patient-report 62%, mean sum clinician-report 84%). Pooling patient-rated items on confidence in therapists/primary contacts, 15% indicated a lack of confidence, 40% indicated 'partly', and 46% 'absolutely'. Figure 2 illustrates ratings of mutual agreement on problems, aims of stay, and confidence in therapists as perceived by patients and clinicians.

Patient-ratings of satisfactory agreement (score = 2) on problems were in concordance with 57% of the clinician-ratings. Correspondingly, patient-ratings of satisfactory agreement on the aims of the hospital stay were in concordance with 65% of the clinician-ratings, and patient-ratings of satisfactory confidence in the main therapist were in concordance with 61% of the clinician-ratings. Comparison of

Patient - therapist mutuality during hospital stay

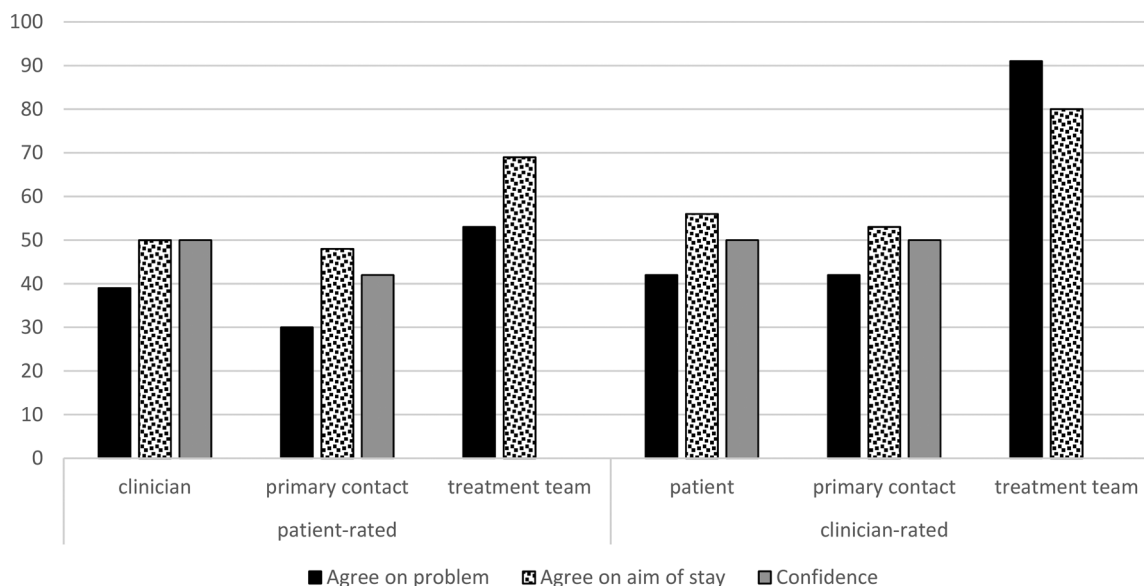


Figure 2. Demonstrates *patient-rated* experience of mutually satisfactory agreement on main problem, aim of hospital stay and experience of confidence in relation to the main therapist (clinician) and the primary contact on the ward. *Clinician ratings* include the corresponding experience of mutually satisfactory agreement between the main therapist and the patient, between the primary contact and the patient and the experience of agreement on problem and aims of stay within the treatment team (therapists and primary contacts on the ward).

patient-rated and clinician-rated scores rendered no significant differences on mutual agreement of problems ($p = 0.552$, $d = 0.1$), mutual agreement of aims of stay ($p = 0.207$, $d = 0.2$) and reported experience of confident alliance ($p = 0.136$, $d = 0.25$).

Mutuality on treatment, follow-up, external collaborator and next of kin involvement were rated by the clinicians (Table 3). Clear agreement with the patient concerning the treatment applied and planned follow-up was reported in 49%, part agreement in 35%, disagreement in 16% (pooled mean, Table 3). Clear agreement between hospital clinicians and other HS on the follow-up was indicated in 59% (pooled mean, Table 2), part agreement in 34%, disagreement in 7% (pooled mean, Table 3). Clinicians reported clear agreement in relation to family/next of kin in 47%, part agreement in 41% and disagreement in 13%.

Discussion

Few former studies have focused on the severe SH subgroup. Based on a unique sample of extensively hospitalized and highly self-destructive patients, findings in the Extreme Challenges project document extensive former health service experience including medical and psychiatric hospitalization, coercion and involuntary confinement [38] (in production). Furthermore, this cohort exhibited a complex array of mental disorders, predominantly PD, alongside other severe mental health, traumatic, and developmental disorders [11]. This study evaluates healthcare and treatment alliance from the perspective of both patients and clinicians in a particularly difficult context. The results indicate 1) *poor patient satisfaction with health care*, 2) *limited availability of specific treatment and supportive measures*, 3) *low ratings of alliance and*

4) *discrepancies between patients and clinicians*. The study lends further support to an evolving picture of a misplaced and seemingly stagnated situation. Approximately one third of the patients lodged formal complaints concerning the treatment, most cases escalated to discussion on a higher administrative hospital level, yet few were reviewed by hospital ethics committees despite the clinical gravity.

Poor satisfaction with mental health care

This study reveals poor satisfaction with primary and mental health care prior to the current hospital admission, moderate satisfaction with the current admission, and significant concerns about discharge. Along the same line, research on patient satisfaction in acute psychiatric inpatient treatment has also indicated particularly poor satisfaction among patients with PD and those subject to involuntary care [39].

Other results from Extreme Challenges note patients' extensive interaction with emergency services starting from an early age [11]. In this study, more than one-third reported that they avoided outpatient emergency services during crises. Research on self-harming and suicidal adolescents emphasized counterproductive effects of adverse interactions with emergency services, exacerbating feelings of distress or not 'deserving' help [40]. Such experiences may aggravate situations in order to be 'taken seriously', or oppositely, induce shame which may limit quality and contact with HS which could stabilize or prevent crises escalation [1].

Approximately two thirds reported somatic hospital service contact before the current admission, and among all services, these contrastingly, rendered far greater satisfaction. Considering their mental health status [11], the dominating mode may be one of utmost helplessness, emotional chaos or detachment and/or lack of self-direction, meaning or hope.

In such a context, the structure of a 24-h clinical setting can offer care and support.

Continuity in health care across service levels

In our study hospital clinicians indicated satisfactory contact and collaboration across services and a high degree of mutuality on this level. These results were more positive than previously reported [13]. A majority of patients were motivated for follow-up and desired inter-service collaboration, though few expected satisfaction and the majority expressed concern about discharge. Clinicians who were concerned reported worry about mental health service follow-up and lack of inter-service cooperation. Continuity of health care and cooperation between services and across health service levels thus appear to be key issues.

Considering the severity of the target situation, availability of intermediary services like ambulatory services, day treatment programs, and scheduled inpatient admissions were lower than expected, covering only a third of our sample. Such treatment modalities could benefit patients with SH and complex and severe comorbidities. Patient-managed admissions have been shown to decrease SH, reduce the duration and frequency of inpatient stays and the extent of compulsory care [41,42]. Brief admissions may render more predictable and more person-centered stays – found beneficial by both patients and staff [43]. Other types of intermediary services with a potential to reduce hospitalization include ambulatory services such as (Flexible) Assertive community treatment ((F)ACT) [44,45]. Tailored, frequent outpatient interventions addressing SH have generally been linked to greater patient satisfaction and lower readmission rates [46]. Considering the high costs involved in repeated intensive hospital treatments, the physical health risks of repeated SH, and mental health burden involved, we emphasize that preventive and supportive, intermediary interventions are highly indicated including not least, targeted guidance of staff/therapists.

Further research on the utility of intermediary – brief inpatient, ambulatory, or intensive outpatient services for complex patients as the current target group is needed.

Few in our study reported follow-up in specialized programs addressing SH or PD. Geographical conditions may limit availability of such treatments, although becoming increasingly available across Norway [47]. An equally timely question is whether patients of our sample could have been helped by such treatments, or whether and how their standardized framework would have been insufficient. While specialized psychotherapy programs have been recommended SH patients [48], their application in severe cases is less clear. Several comprehensive treatment programs have been developed for borderline PD (BPD) – a condition where SH and SA are among the defining criteria [49]. The treatments are mainly in an intensive outpatient format, but day hospital formats are also reported. Positive effects include reduction of SH behaviors, emergency crises, and hospitalizations [50,51]. Further developments have expanded these treatments to a broader range of PDs [52], PD severity [53], and comorbidity [54]. The recent study from the Extreme

Challenges project [11] confirmed personality pathology with 91% qualifying for one or more PDs and a large proportion with BPD. However, the total picture also included extensive comorbidity across developmental, trauma-related and other severe mental health disorders. Such considerable complexity of disorder may limit eligibility to specifically structured PD treatments. A lack of appropriate treatment interventions is likely to contribute to the pattern of extensive hospitalization. With the complex clinical pictures as demonstrated in our former study [11] a suggestion might be to establish stepped care programs integrating inpatient, outpatient, and municipal services.

Alliance during the hospital stay

Patient satisfaction is an important aspect of health service quality where person-related and interpersonal qualities, and the joint engagement between provider and patient are all considered strong determinants [55]. We therefore also included enquiry about the essential experience of a trusting relationship with the therapist, the mutual understanding of problems and the aims of treatment. These features resemble the concept of working alliance, well-established in the field of psychotherapy, and known to be closely associated with outcome [21]. Our results demonstrate a mixed picture where up to half the sample reported satisfactory patient–therapist alliance aspects, while the remaining sample reported limited or no alliance at all. Considering the inpatient context, severe condition, and the importance of a satisfactory alliance for progress [56], including stabilization and change, we conclude that the reports on patient–therapist alliance indicated a clearly suboptimal situation for a large proportion.

Lack of treatment alliance is likely to affect the healing environment, and as such, both clinicians' and patients' hopes for improvement. Patients showed a notable willingness for cross-service collaboration, despite high self-destructivity, suicidal ideation, and dissatisfaction with prior healthcare. One may speculate that participants' desire for change and improvement is present despite severe and long-lasting difficulties and negative expectations. The more complex and severe the patient's situation, the more varied is the outcome of therapy, and the specific therapist matters more [57]. In complex cases, mutually accepted treatment strategies may be difficult to determine.

Working with complex clinical situations, lack of bonding alliance, and recurring severe SH can be discouraging and challenging for health care personnel and contribute to a negatively enforcing spiral. Systematic patient understanding, clear procedures, and specialized teams may be a useful counteraction. Cross-diagnostic inpatient treatment approaches are also advanced for such difficult situations [58], underscoring the complexity of care in challenging circumstances.

Health service use, satisfaction, alliance, and mental health status

The status in this sample with extensive hospitalization, multiple former contact with mental HS and severe and long-term SH risk, suggests limited efficacy of prior interventions. Patients' lack of satisfaction and poor alliance may

not be surprising, nor their pursuit of a more intensive care level. The clinical picture includes overall low functioning in life and few close relations [11]. A disturbed ability to form trusting relationships leads to detachment, loneliness, emotional regulation problems and often a predominance of negative affect. Co-occurring developmental disorders may exacerbate difficulties in establishing reciprocal social relationships. Not least, the high level of traumatization reported in this sample may further aggravate relational anxiety [11]. It is also notable that self-harming behaviors may activate regulatory endogenous responses [59]. In addition, the hospital setting is a concrete care situation. Both may have a soothing effect. A poor capacity to form meaningful and reciprocal caring relationships may thus be an essential dynamic in repetitive SH situations. Further exploration of personality functioning profiles, including both emotional dysregulation as well as alexithymia, attachment patterns and capacity to form bonding interpersonal relationships are all central issues for future research in the current Extreme Challenges project.

Lack of patient–clinician coherence

Rating the utility of the current hospital admission and worry about discharge, patient and clinician reports were often not coherent, and patients indicated greater concern. Furthermore, although clinicians' and patients' alliance-ratings were generally quite similar, clinician ratings tended to be more positive. Reports also indicated higher mutuality within treatment teams in the hospital and across HS than between patient and therapist. Taken together, the results point to a split between the viewpoints of the caregivers and the patient.

Long hospital admissions are often considered not beneficial for patients with SH [60]. Clinician ratings may mirror their emotional responses, with some feeling burdened or unequipped to assist such high-risk patients. The experience may potentially lead to defensive practice and hardness [61], which again may induce a feeling in the patient of being 'too much' for the staff and health care system. The clinician may also fear to be blamed if a patient commits suicide or severe self-inflicted injury. Such fear is often encountered in clinical settings, and therapists may become reluctant to explore problems related to SH or suicide ideation [62]. In sum, complex symptom expressions including SH may yield complex emotional responses in clinicians and staff which again might influence clinical judgments. Enhanced support and education for therapists, including supervision, is a way to mitigate the pressures of managing severe SH cases.

Network and family

The situation is complicated by the high percentage of patients not wanting next of kin to be informed of their situation, thus potentially decreasing the potency of help and support in their everyday lives. The supportive quality of family and close social network may be limited for some patients. A sense of shame around their own condition, surrounding problems, and repeated and/or severe SH acts might also be a part of the picture; shame being positively associated with SH [63]. However, several studies have recommended psychoeducation

and supportive measures addressing families and supportive network for poorly functioning patients [64,65].

Strengths and limitations

This study investigated an under-studied severely self-harming population, in a study with participants from all health regions of Norway. A strength of this study is that missing data were infrequent. All 42 enrolled patients had completed self-report on health service use – for the corresponding clinician-report, data included 35 cases (missing data frequency 17%). Further investigation of differences between the 7 patients who lacked clinician-reported data *versus* the 35 patients with completed clinician assessment revealed no significant trend of difference with respect to clinical status (patient self-report: LPFS-BF and all EQ 5D items including VAS), SH and SA behaviors, and former hospital admissions.

The target situation is severe, but rare, and the included sample is thus small ($N=42$). However, the project recruited the stipulated frequency of patients per hospital [13]. In accordance with the cross regional study scope, all health regions were reflected. However, with larger samples, research could have been expanded to pursue possible differences in SH expression tied to, e.g. different diagnoses.

Further investigation of possible gender differences was not only limited by sample size, but also female dominance. The study can therefore not generalize across genders.

Several of the participating hospitals failed to recruit patients, mainly due to reduced capacity during the Covid-19 pandemic. Among non-participating, invited hospitals, the main given reason for lack of participation was clinicians' limited capacity for extended assessment. Further, the number of enquired patients turning down participating was not recorded.

The naturalistic study-context yielded high clinical representativity where patients were recruited from real life inpatient situations and assessed by clinicians at the hospitals. The project enquired about use of HS across disciplines. A cross sectional study, it excludes longitudinal developments.

The participants' living situation was not systematically traced. Information about this could provide pieces to the severe SH puzzle.

Assessment of health service experiences was based on independent patient and clinician report uniquely designed for the project. To ensure relevance and feasibility all items were developed in collaboration with a project group representing clinicians from hospitals within all health regions and multidisciplinary expert competence including also patient perspectives. It is a possible limitation that next of kin were not directly involved. It is also a limitation that validated instruments capturing this topic and target situation were not available. However, we report the exact questions and answers to ensure transparency.

Conclusion

A positive perception of care is integral to therapeutic outcomes and prevention of future SH. This study highlights an overall dissatisfaction with available help outside the hospital

coupled with a profound lack of trust and therapist–patient dissension within the hospital. The concerns expressed underline the necessity for improved continuum of care. Notably, the limited availability of specialized and/or intermediary/supportive treatment options indicates a gap in the system that fails to address the complex needs of this patient population.

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Author contributions

All authors have contributed actively in the manuscript development. All authors have in addition had at least two active contributions which include designing the survey, project implementation, relevant specialized clinical and/or personal competence, clinician training, data collection, consideration of methods and data analyses and discussion of results. In addition, ØU was the primary initiator of the study focus, and TL, GP, and EHK have had leading roles in project development, implementation and completion. EHK was the principle investigator, engaged in all study phases. GP was responsible for the development of questionnaires, data organization and data collection in the comparison group, TL and EHK were responsible for implementing the project, providing training, feedbacks and webinars for participating clinicians, procedures for data collection and data security, and data analyses and presentation. TL has been responsible for coordinating the data collection, data registration and is the first author of this manuscript.

Disclosure statement

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