CEPHOS-LINK

ENMESH 6-8 JUNE 2019 LISBON, PORTUGAL
13th Conference of the European network for mental health service evaluation (ENMESH)

WAYS TO AVOID RE-HOSPITALISATIONS - MENTAL HEALTH SERVICE USERS' PERSPECTIVES IN SIX EUROPEAN COUNTRIES

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CEPHOS-LINK - Comparative Effectiveness Research on Psychiatric Hospitalisation by Record Linkage of Large Administrative Data Sets

2014-2017

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Partners:

THL, Finland (Project leader)
IMEHPS, Austria
National School of Public Health, Romania
University of Verona, Italy
ZRC SAZU, Slovenia
SINTEF, Norway

European Commission: Research & Innovation FP7 - 603264

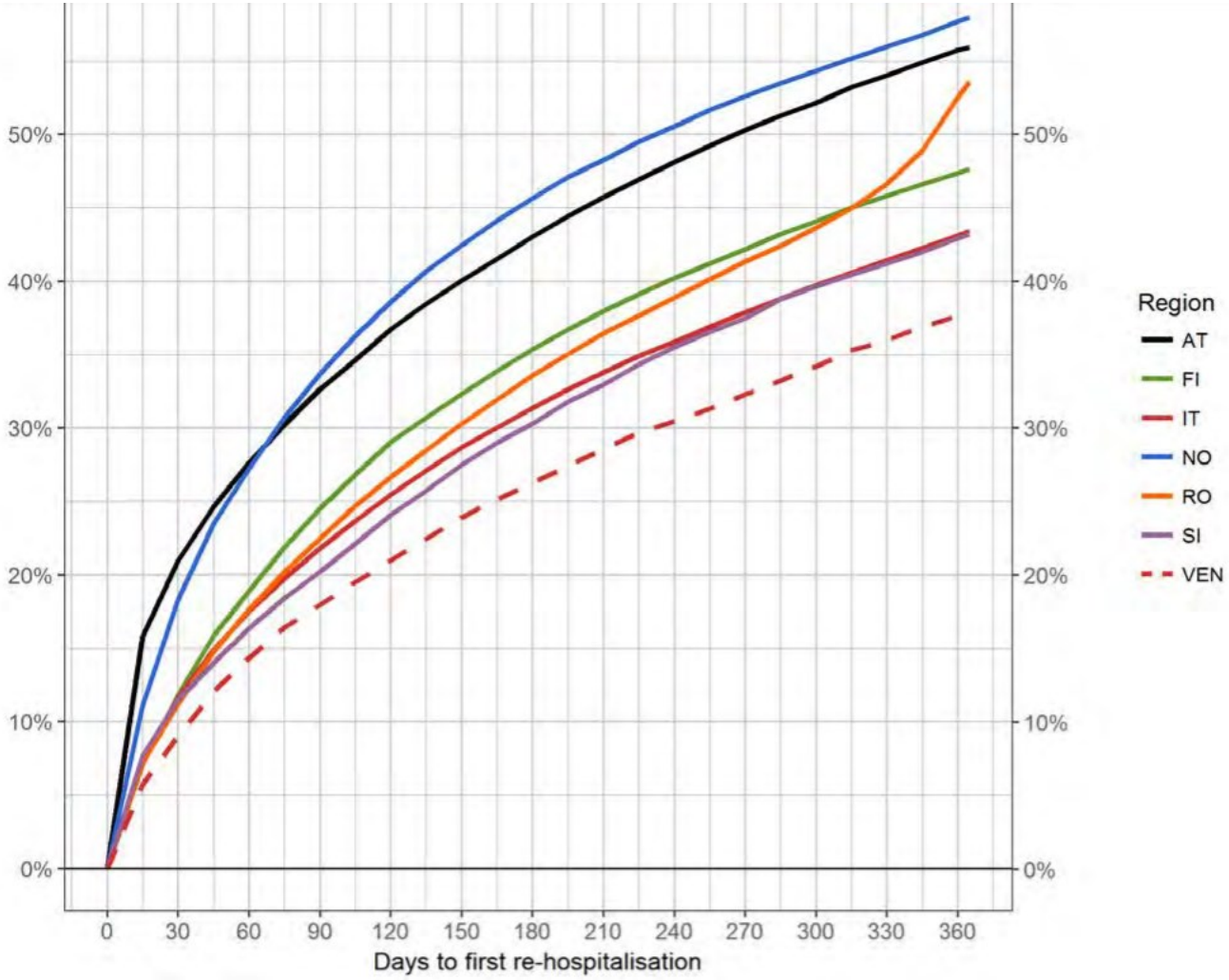
Background

- Psychiatric re-hospitalisation rate often used as an indicator of inpatient care
- Frequent psychiatric re-hospitalisations have been found to be un-favourable both in terms of the quality and cost of healthcare, as well as potentially hampering recovery process (Kalseth et al., 2016; Donisi et al., 2016)
- Psychiatric re-hospitalisation is affected by clinical, social and organisational factors (Tulloch et al., 2015, Machado et al., 2012; Duhig et al., 2017)
- Generally preference of a more patient centred approach (Thornicroft et al 2005)

CEPHOS-LINK lit reviews

- **Pre-discharge factors**: defined on patient/individual level eg discharge type, discharge planning, etc (Donisi et al. 2016)
- **Post-discharge factors**: defined as factors relating to individual characteristics, aftercare factors, community care and service responsiveness, contextual factors and social support.(Sfetcu et al.2017)
- **Environmental and Health System factors**: how health systems are intertwined with patient characteristics (Kalseth et al.2016)
- **Comorbidity**: reviewed the co-occurrence of mental and physical disorders in terms of re-hospitalisation (Sprah et al. 2016)
- **Methodology**: parametric/nonparametric tests, towards regression and survival analyses and modelling and simulation (Urach et al. 2016)

CEPHOS-LINK register study



Cumulative percentage of all re-hospitalisations per country

- Final cohort (N)=225 600
- Many re-hospitalisations occur very early on (often within 30 days)
- In Romania, the increase in re-hospitalisation rates in the last few months of the follow-up period is most probably linked to a regulation for disability pension benefits (at least one hospitalisation must take place over a one year period)
- Database comparability
- Data pooling and methodology

CEPHOS-LINK **focus-group** study

- Recruitment in collaboration with mental health NGO's
- Inclusion criteria:
  - Participant should have experience of psychiatric inpatient treatment more than once.
  - Contact with mental health services for at least one year.
  - As close to equal distribution of gender age and diagnoses.

- Focus group interviews:
  - All interviews took 1.5 hours
  - Researcher from the team led the interview with support from a moderator using standardised interview guide
  - Recorded, transcribed and translated (centrally analysed by SINTEF)

Focus group questions

1. How did it feel like to be hospitalised?
2. How does it feel to have one or more re-hospitalisations, how did it compare to the first admission?
3. What factors may be relevant/important in terms of *avoiding* re-hospitalisation?
4. Is an inpatient stay an experience you are open about, or do you prefer not to share it with other people?

Analysis with Hyperresearch, hR 3.7.3.

Descriptives

Country/city	Number of focus groups	Number of participants
Romania/ Bucharest	1	8
Austria/ Vienna	2	12
Slovenia/ Ljubljana	2	14
Finland/ Helsinki	1	6
Italy/ Verona	1	9
Norway/ Trondheim	1	6
Total	***8***	***55***

Descriptives

Category	Variable	Per cent (N)
Sex	Male	40.0 (22)
	Female	60.0 (33)
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Living situation	Living with parents	12.7 (7)
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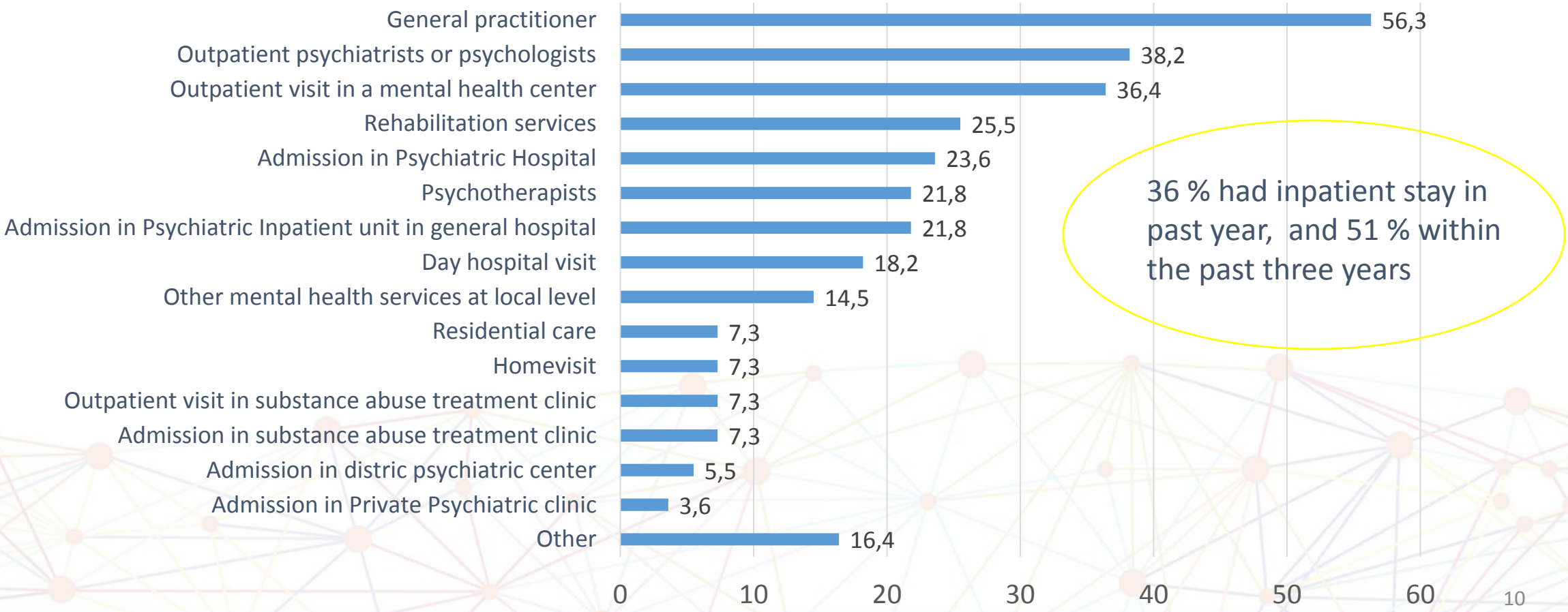
	Living with other co-habitants	3.6 (2)
	Living with other co-habitants in residential care	10.9 (6)
	Living alone	45.5 (25)
Psychiatric diagnoses (multiple entries possible)	Psychotic disorder	41.8 (23)
	Depressive disorder	21.8 (12)
	Bipolar disorder	38.2 (21)
	Anxiety disorder	9.5 (7)

Contact (min 1) with mental health services in the last year % (n=55)



36 % had inpatient stay in past year, and 51 % within the past three years

Explorative focus group study

Theme 1: Re-hospitalisation as less traumatising than the first hospitalisation

Theme 2: Re-hospitalisation seen as necessary and a relief

Theme 3: Re-hospitalisation seen as inevitable and occurring by default but without progress

Theme 4: Re-hospitalisation as part of a recovery process

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RESEARCH ARTICLE Open Access

Mental health service users' experiences of psychiatric re-hospitalisation - an explorative focus group study in six European countries

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Abstract

Background: Psychiatric re-hospitalisation is considered costly and disruptive to individuals. The perspective of the mental health service user is largely unexplored in literature.
The purpose of our study was to explore service users' experiences of psychiatric re-hospitalisation across six countries in Europe.

Method: Eight focus groups were conducted in Romania, Slovenia, Finland, Italy, Austria and Norway.

Results: A total of 55 service users participated in the study. All participants had been in receipt of mental health services for at least 1 year, and had experienced more than one psychiatric hospitalisation. The experience of re-hospitalisation was considered: (1) less traumatising than the first hospitalisation, (2) to be necessary, and a relief, (3) occurring by default and without progress, (4) part of the recovery process.

Conclusions: Psychiatric re-hospitalisation was considered inevitable by the study participants, in both positive and negative terms. Striking similarities in service user experiences were found across all of the six countries, the first experience of psychiatric hospitalisation emerging as especially significant. Findings indicate the need for further action in order to develop more recovery and person-centred approaches within hospital care. For psychiatric inpatient care to be a positive part of the recovery process, further knowledge on what therapeutic action during the hospital stay would be beneficial, such as therapy, activities and integration with other services.

Current study objectives

- How can psychiatric re-hospitalisation be **avoided?**
- What are service users own experiences in terms of strategies, and measures to avoid new re-hospitalisations?

Main findings (themes)

Factors were mentioned as important for **avoiding** psychiatric re-hospitalisation:

Theme 1 Plans and preparation for discharge during hospital stay

Theme 2 Comprehensive follow-up after discharge

Theme 3 Self-monitoring and mastery through structured plans

Theme 4 Social inclusion and meaningful activities

Theme 5 Informal support from community and from family and friends.

Theme 1: Plan and preparation for hospital discharge during hospital stay

- Important to **receive information** about local services

  -> Both for follow up from mental health services, and also for avoiding loneliness and lack of daily structure

"What would help me in hospital as a preparation for discharge, I think, is if I can already have talks in hospital: what the next 1 or 2 weeks will look like, not only that I know I have a social worker at the psychosocial service, but also that I can make an appointment while being in hospital. (…)

At the same time, I can call these people, so that my psychosocial quasi-network is starting again, but that is really hard for me after a hospital stay, that may be too much again, immediately [after discharge]."

Theme 2: Comprehensive follow-up after discharge

- Need for regular contact with mental health services in order to monitor symptoms and medication (traditional health service), more extensive and frequent follow-up, in order to identify change and development
- Need for psychosocial support measures eg telephone calls (simple solutions)
- Need for an intermediate - liaising between formal, traditional mental health services and more informal services, eg mobile services / home services

"it's just talking, and then it is back to reality"

"..alternative psycho-social institutions are simply available far too little, and, in my case it also happened often, because I simply have these bad experiences with emergency psychiatry, I try to *avoid* that as long as possible, but there is no alternative I think. (...) when one is beginning to "burn" somehow, I can't work it out by myself anymore, but it is not acute yet either(…) and somehow something in between (is needed), yes."

Theme 3: Self-monitoring and mastery through structured plans

- Emphasis on usefulness of structured plans eg crisis planning, treatment plan, coping, identify when to contact services
- Need for information on medication and how to identify changes in dosage need (in collaboration with MH professional)
- Looking after yourself (diet, exercise, social contacts etc)

"Before that it was called a crisis plan. Crisis and acute. Now it's called the master plan. You get responsibility, and you have the right to your own situation. There is (…) a chapter on warning signs. What is the symptom of getting ill? What you should do. () Then, as I mentioned, the warning signs…which you have made when you were well, warning signs and... who to contact."

Theme 4: Social inclusion and meaningful activities

- Day centers and activity centers have a highly important role for meeting need for structure, activity, training, social contact and meaning in daily life.

"You get meaning back, and more structure, and fixed agreements and stuff, so I have thought of it that if I had this...before then I could have shortened the period a lot.“

"I go to the meeting place run by the municipality, and I think that it is absolutely invaluable. Opportunity to go there and relax, meet other people, to paint etc. If they close down this place..I mean, it is more expensive to treat people than to rehabilitate people. So, that way you would think that places like this should be maintained."

Theme 5: Informal support including support from family and friends.

- **Support group can feel safer than by professional support because this "cannot lead to admission".**
- Ideally combine family and friends support and professional support participants discussed various models - eg family / friends support that could start already during the hospital stay
- Support from family very valuable, but is dependent on good relations

"I have also, where I live, a place where we can come and go and do all sorts together and have **peer support groups** where we discuss and I have learned that, it has been there for like 11 years that place, and you actually see how people have become stronger and not needed to be taken into hospital."

Conclusion

Results indicate many ways of avoiding psychiatric re-hospitalisation by taking advantage of resources at all levels:

- **Institutional level** - better planning for discharge from an admission
- **Community** (service) level - need for more extensive and frequent follow-up, to identify changes/development - can be simple measures
- **Personal level** "self-monitoring" - eg through crisis/master plan to identify changes
- **Social level** - be part of social community - "being seen"
- **Relational level** - the benefit of using family and friends more consciously and purposefully

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Publications

www.cephos-link.org

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Bakgrunn

- Hyppige reinnleggelser oppfattes som ugunstig både når det gjelder kvalitet, kostnaden for helsetjenester, og når det gjelder recovery/ tilfriskning (Kalseth et al., 2016; Donisi et al., 2016)

- Reinnleggelse påvirkes av en rekke kliniske, sosiale og organisatoriske faktorer (Tulloch et al., 2015, Machado et al., 2012; Duhig et al., 2017)

Brukeres opplevelse

- Brukere opplever gjerne innleggelse som *nødvendig* og som en *lettelse*, OG som noe som ofte skjer *"standardmessig"* eller med *tvang* – ofte *uten framgang eller bedring* i situasjonen (Ådnanes et al., 2018; Rise et al., 2014; Duhig et al., 2017)

- Foretrekker gjene intervensjoner som støtter *brukersentrert tilnærming* med fokus på *personlige mål* i samfunnet (Johnson et al., 2018; Thornicroft, Bebbington og Leff, 2005)

Mål for studien

- Hva bidrar til å unngå reinnleggelse?
    - Hva er brukeres erfaringer når det gjelder strategie ressurser og tiltak som kan bidra til å unngå nye innleggelser?

Metode - fokusgrupper

- Fokusgrupper er egnet metode for å skaffe seg kunnskap om pasienters erfaring med behandling eller helsetjeneste (Malterud, 2012)

Metode - fokusgrupper

- Samarbeid med brukerorganisasjon om rekruttering og fokusgruppe
- Utvalgskriterier:
  - Personer innlagt i psykisk helsevern mer enn en gang
  - Kontakt med psykiske helsetjenester i minst ett år
  - Forøvrig god spredning når det gjelder kjønn, alder og diagnoser

- Gjennomføring fokusgruppeintervju
  - Varighet 1,5 time (alle intervjuene hadde denne varighet)
  - Forsker ledet intervjuet + medfasilitator
  - Opptak, transkribering og oversettelse (SINTEF analyserte alle)

Utvalg

Country/city	Number of focus groups	Number of participants
Romania/ Bucharest	1	8
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Hovedspørsmål i intervjuet

Hovedspørsmål i fokusgruppeintervjuet:

- Hvordan opplevdes det å bli innlagt for første gang i psykisk helsevern?
- Hvordan oppleves det å bli lagt inn på nytt/flere ganger (og sammenligna med den aller første innleggelsen)?
- **Hvordan kan man unngå reinnleggelse? (spesifikt for denne artikkelen)**
- I hvilken grad oppleves en innleggelse som stigmatiserende?

- Analyse ved bruk av Hyperresearch, hR 3.7.3.

Beskrivelse av utvalget

Category	Variable	Per cent (n) N
Sex	Male	40.0 (22)
	Female	60.0 (33)
Age (years)	26–35	22.2 (12)
	36–45	24.1 (13)
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	Depressive disorder	21.8 (12)
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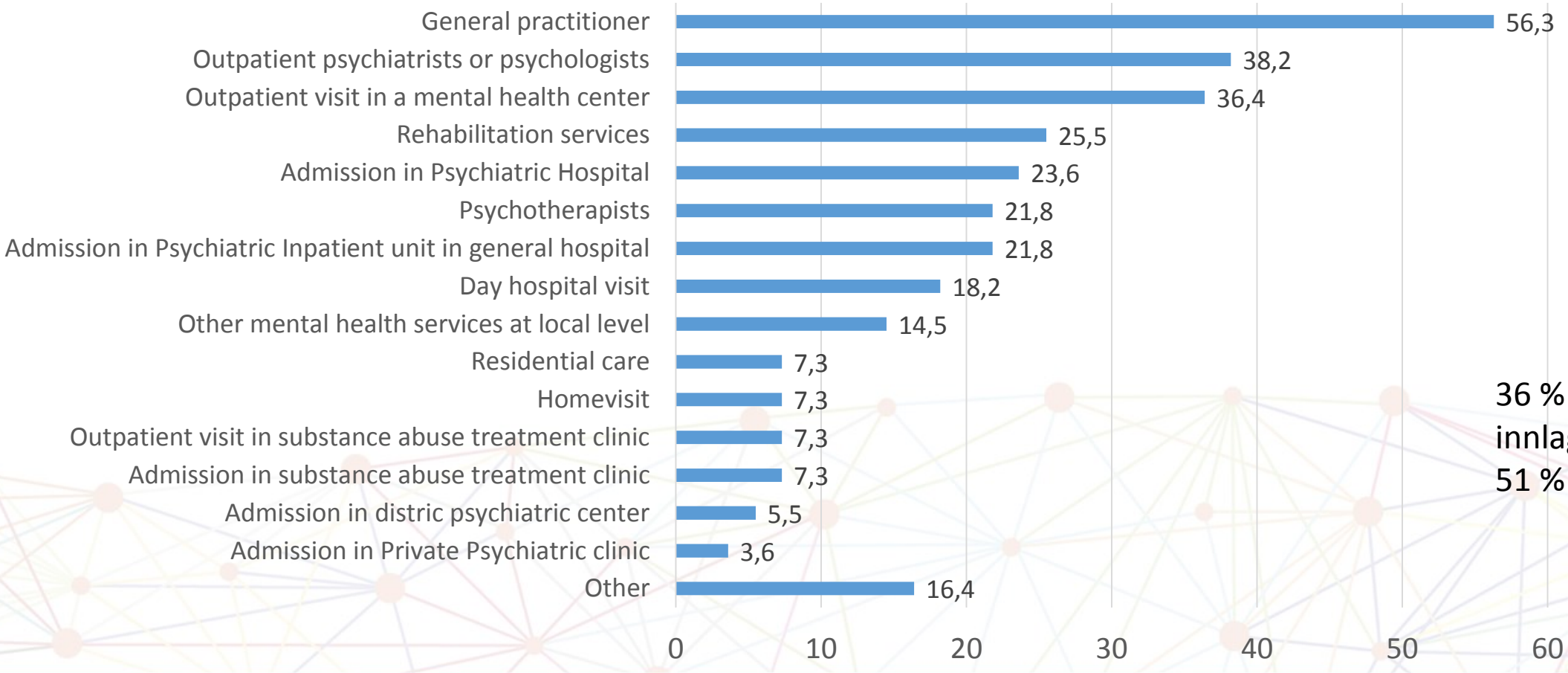
Kontakter (minst en) med psykiske helsetjenester siste år (n=55). Percent



36 % hadde vært innlagt siste året, og 51 % siste tre årene

Hovedfunn fra fokusgruppene

Brukerne mente følgende faktorer var viktig for å unngå reinnleggelse:

1. Planer og forberedelser for utskriving mens man er innlagt
2. Omfattende oppfølging etter utskriving
3. Selvovervåkning og mestring gjennom strukturerte planer
4. Være del av sosialt fellesskap + meningsfulle aktiviteter
5. Uformell støtte, inkludert støtte fra venner og familie

Tema 1) Planer og forberedelser for utskriving mens man er innlagt

- Få *informasjon* om tilgjengelige tjenester
- Lære *mestringsstrategier* gjennom strukturerte planer
    - både for oppfølging fra tjenestene + unngå ensomhet og mangel på struktur

"What would help me in hospital as a preparation for discharge, I think, is if I can already have talks in hospital: what the next 1 or 2 weeks will look like, not only that I know I have a social worker at the psychosocial service, but also that I can make an appointment while being in hospital. (…)

At the same time, I can call these people, so that my psychosocial quasi-network is starting again, but that is really hard for me after a hospital stay, that may be too much again, immediately [after discharge]."

Tema 2) Omfattende oppfølging etter utskriving

- Behov for jevnlig kontakt med tjenesteapparatet for å følge med på symptomer og medisinbruk etc. (tradisjonell helsetjeneste)
  - Men behov for *mer omfattende og hyppig oppfølging*, for å kunne identifisere endring og utvikling, for slik å følge sykdomsforløpet nærmere
    - Psykososiale tiltak og enkle tiltak som telefonoppringing
    - Intermediære – mellom formelle, tradisjonelle psykisk helsetjenester og mer uformelle tilbud, f.eks mobile tjenester/hjemmetjenester

"it's just talking, and then it is back to reality"

"..alternative psycho-social institutions are simply available far too little, and, in my case it also happened often, because I simply have these bad experiences with emergency psychiatry, I try to *avoid* that as long as possible, but there is no alternative I think. (..) when one is beginning to "burn" somehow, I can't work it out by myself anymore, but it is not acute yet either.. and somehow something in between (is needed), yes."

Tema 3) Selvovervåkning og mestring vha strukturerte planer

- Stor vekt på nytten av strukturerte planer
  - F.eks Kriseplan / mestringsplan for å identifisere endringer som tilsier kontakt med psykisk helsetjeneste
- Behov for kunnskap om medisinering og endringer i tilstand som tilsier behov for endringer mht medisin
- Ta godt vare på seg selv (mat, fysisk aktivitet, sosial kontakt etc)

"Før het det kriseplan. Krise og akutt. Nå heter det mestringsplan. Man får ansvar, og råderett over sin egen situasjon. Der står det som sagt ett kapittel om faresignal. Hva er symptom på at jeg blir syk. Hva skal du gjøre. () Da er det som sagt varselsignal..man har gjort en avtale når man er frisk, på hva er det som er tegnene på .. hvem skal man kontakte."

4) Være del av sosialt fellesskap + meningsfulle aktiviteter

- Den svært viktige rollen til dagsentra, aktivitetssentra
  - Svært viktige i å møte deltakernes behov for struktur, aktivitet, opplæring, sosial kontakt og mening i det daglige livet.
- Boligomsorg svært viktige for enkelte

"Da får du mer mening tilbake, og mer struktur, og faste avtaler og sånt, så eg har tenkt på det at hvis jeg hadde vært innom x (dette tilbudet) før så hadde jeg kunne korta ned forløpet mye."

"I go to the meeting place run by the municipality, and I think that it is absolutely invaluable. Opportunity to go there and relax, meet other people, to paint etc. If they close down this place..I mean, it is more expensive to treat people than to rehabilitate people. So, that way you would think that places like this should be maintained."

5) Støtte fra familie og venner

- Kan føle seg tryggere i en støttegruppe enn ved profesjonell støtte fordi dette "ikke kan føre til innleggelse". (sitat)
- Kombinere familie og venners støtte + profesjonell hjelp
  - Deltakere diskuterte ulike modeller – f.eks familie/venner-støtte som kunne starte allerede under sykehusoppholdet
- Pårørendestøtte verdifullt, men er selvsagt avhengig av gode relasjoner

"I have also, where I live, a place where we can come and go and do all sorts together and have **peer support groups** where we discuss and I have learned that, it has been there for like 11 years that place, and you actually see how people have become stronger and not needed to be taken into hospital."

Konklusjon

- Resultatene viser flere veier til å unngå reinnleggelser :
- Oppsummert handler det om å få til større utnyttelse av ressurser på alle nivå:
  - Institusjonsnivå (bedre planlegging for utskriving fra en innleggelse)
  - Kommune(tjeneste)nivå (behov for mer omfattende og hyppig oppfølging, for å kunne identifisere endring og utvikling, for slik å følge sykdomsforløpet nærmere – kan være enkle tiltak)
  - Personlig nivå ("selvovervåking" - f.eks gjennom *Kriseplan* for å identifisere endringer som tilsier kontakt med psykisk helsetjeneste
  - Samfunnsnivå (være del av sosialt fellesskap – positivt i seg selv, og innebærer også å "bli sett")
  - Relasjonelt nivå (nytten av å bruke familie og venner mer bevisst og målrettet)

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