

MentALLY*

Project results I: How do people experience mental healthcare?



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*The MentALLY project is a pilot project which has received funding from the European Parliament. Pilot Projects is an initiative „of an experimental nature designed to test the feasibility of an action and its usefulness“ and permits appropriations for it to be entered in the EU budget for more than two consecutive financial years.

Mental healthcare in six European countries
from a perspective of people with lived
experiences:

A focus group study within the MentALLY
project

Collaborative effort

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Background

- ▶ Mental disorders are among the dominant causes of non-fatal health loss in Europe
- ▶ 17.3% (n = 84 million) of the European population
- ▶ Challenge for politicians and healthcare providers all over Europe
- ▶ Access to high quality mental healthcare
- ▶ Most studies and reports of mental healthcare provision in Europe are based on quantitative data
- ▶ Qualitative studies contribute to an in-depth understanding

Aim

- ▶ To explore experiences of mental healthcare in six European countries regarding access, diagnosis, referral, treatment and collaboration among adult Europeans with lived experiences of mental health problems

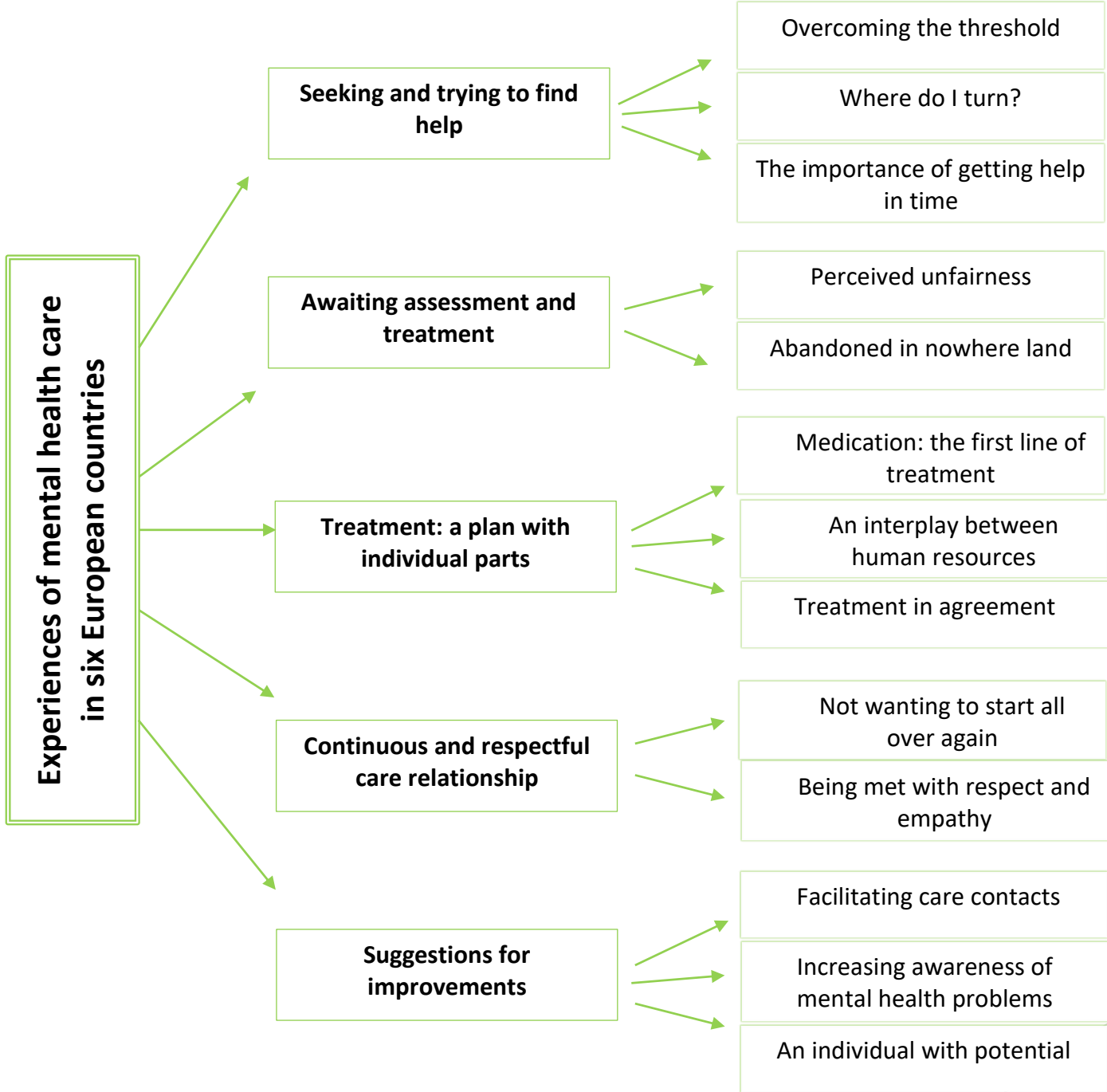
Method

- ▶ Focus group interviews
 - ▶ 50 participants with lived experiences of various mental health problems and a wide range of mental health care.
- ▶ Interview guide
- ▶ Thematic analysis
- ▶ Ethical approval



Table 2. Overview of the focus group interviews and participants

	Belgium	Cyprus	Greece	Netherlands	Norway	Sweden
Number of focus groups	1	2	1	1	1	1
Length of focus groups in minutes	132	73+126	141	123	100	118
Number of participants	14	4 + 4	8	7	6	7
Male participants Age range in years	6 48-63	3 + 2 50-56, 30-32	4 32-55	2 45-69	1 45-55	2 29-48
Female participants Age range in years	8 24-54	1 + 2 45, 50-52	4 32-45	5 44-67	5 40-70	5 27-63



Seeking and trying to find help

Overcoming the threshold

- ▶ Accept and acknowledge
- ▶ Public stigma
- ▶ Problems to afford
- ▶ Previous experiences

Where do I turn?

- ▶ Not find the way
- ▶ Not know where to turn
- ▶ By chance
- ▶ Own network

The importance of getting help in time

- ▶ Waiting times
- ▶ Desperate situation
- ▶ Life or death
- ▶ Resignation

- ▶ "Someone may suffer from a mild depression and leave it without treatment because of what society is going to think". (1 Cyprus)
- ▶ "Well, I am thinking about when you don't know exactly where to turn to. Where do I go, what should I do, who should I talk to? It does seem pretty unclear. Where do I begin, where do I call?" (2 Sweden)
- ▶ "Yes, I had to wait several times for a long time. But at the same time, 3 weeks are hellish as well. When you are suicidal for 3 weeks, it becomes too much." (1 Netherlands)

**Awaiting
assessment and
treatment**

**Perceived
unfairness**

- ▶ Not prioritized
- ▶ Not carefully assessed
- ▶ Exaggerate their mental health problems

**Abandoned in
nowhere land**

- ▶ Tiresome referral process
- ▶ Gaps between levels of care
- ▶ No care chain

- ▶ “I would want it to be easier to get help. Because I have said so many times that I want help, but then I do not get it. And they say to the patients: “have you tried taking your own life”, and “no, then you do not get to be admitted”. But you need to be admitted before you get so sick, in order to avoid getting sick.” (1 Norway)
- ▶ “When the doctor saw me, he said “you have schizophrenia”. He just looked at me! He did not examine me for more than one minute and he diagnosed me with schizophrenia.” (1 Greece)
- ▶ “That it is very difficult, that you must just keep on nagging and fighting, to fight a lot and you don’t have the strength to do that. I find that it is a huge problem, when you are waiting, because you are in the care queue and waiting for a referral, and waiting for something to happen with the referral, and then you just have to keep at them, you have to call, you have to nag, and you don’t have the strength, so you just wait, quiet and being nice. So not much happens. That’s my experience.” (2 Sweden)

Treatment: a plan with individual parts

Medication: the first line of treatment

- ▶ Avoid negative outcomes
- ▶ Over-prescription
- ▶ Not the only solution

An interplay between human resources

- ▶ A whole person
- ▶ Different competencies
- ▶ Active part
- ▶ Social health

Treatment in agreement

- ▶ Consent
- ▶ Involuntary

- ▶ ”I would be unable to function right now without the medication. I'd be much worse if I didn't take it. Much worse. The medication I'm taking helps me a lot. If it weren't for it, I'd take drugs, or start drinking. Taking it is in my best interest - not the doctor's or the pharmacist's.” (4 Cyprus)
- ▶ “Actually the best therapists are those who have experienced it themselves... and sometimes I wonder that is a kind of... if my psychiatrist is sitting in front of me, that is book knowledge... that person can never know what a depression is, that person can never know what an eating disorder is, he knows it but just due to experience, but that person cannot... at first-hand experience it. And the biggest help I got was actually from people with the same problems.” (1 Belgium)
- ▶ “But it is important to address all problems the person is presenting. It is not certain that the psychiatry or the substance abuse is the worst. It could be economy, it could be living conditions, there are many other things that play a role, it is not only psychiatry” (1 Norway)
- ▶ “This distressed me too much because they took me with handcuffs; they took me in a patrol car as if I was some criminal. And this hospitalization was a horrible experience for me. And I have not been able to overcome it and I will never overcome it. They brought me in with handcuffs as though I was a criminal”. (1 Greece)

Continuous and respectful care relationship

Not wanting to start all over again

- ▶ Explain everything all over again
- ▶ Continuity
- ▶ A steady care contact

Being met with respect and empathy

- ▶ Being vulnerable
- ▶ Stigmatizing attitudes
- ▶ Oppressive
- ▶ Empathic ability

- ▶ "Then just to have a person...yes, partly to one who is...sort of like a coach for that person, a little like a mentor or coach, and that it is one person, so that they are not replaced all the time so you get new people. It is also important that you have regular staff" (1 Sweden)
- ▶ "I wish for better attitudes among healthcare professionals, especially when it comes to the most serious diagnoses. There is a lot of prejudice and stigma, and you often get treated as a diagnosis, and I think that is condemnable." (6 Norway)
- ▶ "It means empathy; being able to understand the problem so you can help. It means therapists themselves should be able to feel what each one of us is going through. Because if you don't, you can't help". (5 Cyprus)

Suggestions for improvements

Facilitating care contacts

- ▶ Emergency reception
- ▶ Knowledgeable contact point
- ▶ Explanation of treatments
- ▶ Geographical spread
- ▶ Mobile teams

Increasing awareness of mental health problems

- ▶ Proactive efforts
- ▶ Experts with experience

An individual with potential

- ▶ Strengths
- ▶ Ability
- ▶ Illness - health

- ▶ “It would like to have a kind of basic post for mental healthcare. Kind of like an First aid, where you could go for help. It would help lots of people. There would be a faster process, instead of the long waiting lists. It would cost the taxpayer less as well.” (1 Netherlands)
- ▶ “I think that, instead of having a bigger building, the facility should spread to other cities...//... We need to have such facilities close to us. It's not enough for me to come here and see a doctor for 10 or 30 minutes. Or to have to wait for 3 months, for 2 months at least or for 1 month until the date of my appointment comes”. (2 Cyprus)
- ▶ “So, I think there should be an education campaign. ...//... we need to get to young people in schools. So that young people know what can happen to anyone. Because what's happening to me may happen tomorrow to my neighbour. They should know how to handle it, know how to deal with it. Now there are drugs, treatments, and institutions. There are many good and remarkable doctors. So, I think people need to be informed”. (3 Greece)
- ▶ ”To treat an illness is also to...you need to sort of treat the people who are ill ...//... strengthening the healthy, because focusing too much on the illness makes you more ill, and then it is easy to be, sort of...it goes in a ring, a downward spiral. (4 Sweden)

Conclusions

- ▶ Difficult to access mental healthcare
- ▶ More accessible through mobile teams and e-health
- ▶ A steady contact can facilitate
- ▶ Mental health treatment needs to be tailored for each individual containing more parts than medication but with the addition of an empathic respectful encounter.
- ▶ Increased collaboration between stakeholders in society to act on stigma
- ▶ Improvement of mental health literacy is warranted

References

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Thank you very much
for your attention!