Mental healthcare users' experiences with the accessibility and effectiveness of mental healthcare:

A focus group study in six European countries

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The European MentALLY project

Mental health problems in adults are of great concern, as they are highly prevalent and impact significantly on health, social welfare, and the economy. Various types of mental health treatment (psychotherapy, pharmaceutical treatment, etc.) have proven to be effective, but they have not been able to nullify the apparent disparities within mental healthcare. There is suboptimal or undertreatment of some adults and overtreatment of others. MentALLY's strategic aim is to gather the necessary empirical evidence to accelerate the evolution towards European mental healthcare that provides effective mental health treatment to all adults who are in need.

Six countries

- Sweden & Norway
- Belgium & The Netherlands
- Greece & Cyprus

The issue

We currently lack data on the current situation in mental healthcare across Europe and on the practices required to overcome barriers in access to services, in assessing and referring mental healthcare users, and providing the most efficient and effective care to those in need. The experiences of (former) mental healthcare users might be of particular interest in examining these issues.

Research questions

1) What are **mental healthcare users' perspectives** on good and bad practices in current mental healthcare?

2) What are examples of good and bad experiences of mental healthcare users related to **access, diagnosis and referral,** the **treatment** itself, and **collaboration**?

Method

Local **focus groups** with 6–14 participants in **6** countries

- A focus group is a qualitative research method whereby various participants have a discussion on a particular topic. The discussion is led by a facilitator (or multiple facilitators) who provides a list of topics concerning the main research questions.

- Ethical approval from four Review Boards: Ghent University, University of Gothenburg, the University of Crete, and Regional Committees for Medical and Health Research Ethics Norway

- Research process in each country: **recruitment of participants → informed consent → audio-recorded focus group → verbatim transcript → translation to English → thematic analysis**

- Participants were recruited according to the following criteria: age – gender – experienced mental health problems (e.g. depression, addiction, psychosis) – former user of a mental healthcare facility (as either an inpatient or an outpatient, in private or public services).

Thematic analysis

The thematic analysis followed the step-by-step instructions presented in Braun & Clarke (2006)[1] with the goal of identifying patterns that are relevant to our research questions. The analysis resulted in a series of main themes and subthemes for each country. The resulting themes and subthemes were woven together to summarize, interpret, and make sense of the data in a narrative representing the six MentALLY partners' engagement in sharing and recounting the mental healthcare stories in their countries. In this fact sheet, we present eight general findings that refer to themes and patterns that were present in various focus groups across the six countries.[(*)]

(*) The findings in this fact sheet are the result of a first analysis of the focus groups across all countries. For a more extensive description of the thematic analysis within each country, the resulting themes, and an analysis between countries, we would like to refer to the academic paper that will be published in a later phase of the project. More information on this paper will be shared on the MentALLY website: http://mentally-project.eu.

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[1] Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology, 3*(2), 77-101.

Findings

(1) Need for better and immediate accessibility

Long **waiting lists** are mentioned as one of the barriers to receiving help for mental health problems. Participants note that often no immediate help is possible if problems are not 'serious' enough. In some cases this even leads to people putting themselves in danger in order to get help more quickly (e.g. making a suicide attempt) or while waiting for help (e.g. self-medicating). Another problem regarding access is the **geographical barrier** to getting help. Especially in Cyprus, it is mentioned that there are not enough mental healthcare facilities across the country.

(2) Need for continuity in care

Participants express the desire to have someone who could guide them through the various steps in mental healthcare. This person could be a **confidant** to the client. Participants report having experienced problems in the referral from one practitioner to another, hereby sometimes feeling as if they end up in 'nowhereland'.

(3) Importance of freedom of choice in treatment

Severel participants experience a lack of control in treatment planning. **Treatment with psychotropic medication** can often be psychiatrists' first choice. As a result, participants sometimes felt as if they didn't get the best treatment. Although they do recognize the importance of medication, they feel as if other treatment options should also be explored in a more thorough way. Some participants mention that they did not feel as if they had a choice in whether or not to take medication. Furthermore, **involuntary hospitalizations** are experienced as traumatizing by several participants. The consent of the patient should be considered at every step in the process..

(4) Request for an individualized approach

The feeling of being a number and not being cared for in an authentic way is one of the participants' complaints. They want to be treated as people, with all their strengths and vulnerabilities taken into account. They would like practitioners who focus not only on the problems, but also on the client's individual strengths and their context (work, family, etc.). In summary, they long for a more **personalized and holistic approach** in therapy.

*"You need to treat the **people** who are ill, not just the illness."*
(Swedish participant)

(5) Importance of respect

Participants emphasize the importance of **confidentiality**. They also request **enough time** (especially with general practitioners) and express a desire to get rid of **power relations** between client and practitioner. They also wish to be met without **prejudice**. They feel as if decisions in mental healthcare are sometimes based on prejudices regarding a diagnosis. In addition, they report experiences of not being believed when voicing physical complaints since 'it must be all in their heads'. They feel as if mental health issues are not always taken seriously.

"When it comes to physical problems they do not just send someone home. They do not say 'Yes. It's cancer. Just rest up a bit and perhaps the tumor will shrink'." (Dutch participant)

(6) Importance of clients' expertise

Practitioners should acknowledge the expertise that clients have and learn from it. In addition, **experts by experience** in mental healthcare and **peer-support** groups are seen as an important supplement to the main services provided.

"The best therapists are the people who experienced it themselves."
(Belgian participant)

(7) Need for information on mental health problems

Mental health problems are often not noticed until they get very serious. There is a need in several countries for more **awareness** of the existence of mental health problems and their warning signs In addition, Cypriot participants mention the experience of a **lack of information** on the availability of certain mental health services.

(8) Time to break the stigma

Participants express the need to get rid of the stigma concerning mental health. They feel as if the media could help by providing more **positive stories** of people who experience mental health issues. In addition, they also recognize their own role in breaking down stigma by telling their own stories.

Conclusion

Accessible mental healthcare

- Participants in various countries across Europe express the need for better access to mental healthcare. Long **waiting lists** are named as one of the main barriers to accessing help. Whereas in some countries participants do not express any problems regarding the **availability** of mental healthcare, in other countries they do. Participants also voice the need for a **better referral process** and suggest the presence of **a confidant** to guide them throughout this process.

Effective mental healthcare

- Participants emphasize the importance of **respect**. They want to be treated as a person, not as a number. They long for an **individualized approach** in mental healthcare whereby both their vulnerabilities and their strengths are taken into account. They would like to be involved as much as possible in the **choice of treatment**. Various treatment options should be explored at all times. Although they recognize the importance of medication, most former mental healthcare users do not believe this is the only path to be taken. They believe that the combination of different kinds of treatment and approaches would be most effective in helping them. **Peer-support** and involving **experts by experience** are seen as very valuable in the treatment of mental health problems. Participants underline the presence of **stigma** in the way we think about mental health. The media often portrays mental health issues in a negative way, but (mental) health professionals also sometimes stigmatize their clients. There is a need for more positive stories. Former mental healthcare users believe that they might have a role to play in the destigmatization movement.