

# “a struggle to be connected in disconnecting times”

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This study is part of a larger study focusing on the impact of the Covid pandemic on mental healthcare and how this crisis is experienced by patients, relatives and caregivers. This summary in particular focuses on the experiences of the relatives of people with serious mental health problems. Our objective was to get an insight in how they cope with these exceptional circumstances and how they experience their relationship with the caregivers (in our study, we define caregivers as the mental health practitioners). The title of our e-poster already gives you a sneak preview of what relatives in these Covid-times endure, what is described as “a struggle to be connected in disconnecting times”.

For this research a phenomenological research design was employed. 15 semi-structured individual interviews with relatives from a variety of organizations in Flanders (Belgium) were carried out. Data-analysis was achieved by thematic analysis. Intensive rounds of research triangulation were set up to validate the data.

## **Sense of attunement and connection**

The study unraveled hindering and promoting factors affecting relatives’ sense of attunement and connection with caregivers and patients during the care process.

Experienced communication barriers, lack of information and possibilities to contribute to the care process, being withheld from being together with the patient and the continuous struggle to hold on, were identified as key factors increasing relatives’ sense of disconnection.

Relatives experienced the COVID times as an intense time-span for themselves. In the interviews the relatives spoke out freely about their daily challenges they had to face. They not only had to cope with the stress of quarantine and social distancing, but they also felt responsible to keep running and managing the housekeeping, the care for the children, or to cope with income decline or unmanageable debts, etc. Relatives also mentioned how they experienced the Covid times as disturbing and confusing in relation to their family member and the responsible caregivers.

On the one hand, relatives were confronted with an information overload related to COVID in their daily life, and talked about how it was hardly impossible for them to process all this information. On the other hand, relatives mentioned how they felt being kept in the dark related to what was happening in the mental health care facility and how they could only rely on the information provided by their family members. In case the relationship with their family member was already under pressure for a longer time, relatives were even more unsure if the information provided was not prejudiced.

Analysis of the interviews not only generated hindering factors, but also promoting factors. Being acknowledged, understood and supported by approachable caregivers were experienced as crucial to reconnect with the patient and the caregivers.

### **Pivotal role of nurses**

Being connected or disconnected was a key insight derived from the analysis of the interviews with the relatives in this study. Moreover they experience a dependency in their relationship with caregivers, as caregivers can give them a voice to be heard and can open up experienced barriers to be involved in the care process, or to initiate contact with them at the early start of the care process.

Caregivers (and nurses in particular) can assume a pivotal role in connecting with relatives as they are their first point of contact. Caregivers are in charge of the organizational policy and rules and how these are translated in the contact and communication with relatives. If they know what really matters for relatives, caregivers can align the measures in harmony with the needs of relatives. Relatives also highlight how caregivers can assume an advocacy role on behalf of both relatives and patients. Taking up this advocacy role is an important step to engage relatives in the care process. Therefore, caregivers and in particular nurses have many opportunities to explore openly and in a dyadic way from the very early start of the care process the needs of the relatives and how they want to be involved in the care process. It is necessary to reassess these experienced needs and the agreed level of involvement regularly, as they may differ over time and may vary from relative to relative. This approach not only gives clarity for all who is involved, but also contributes to acknowledge and empower relatives as full partners in the care process. Moreover, it can help to cancel out the feeling of disconnection experienced by relatives, which was a central theme in this study.

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