

# Persons with psychotic disorders` experiences with family involvement

*09.02.2023*

Kristiane M. Hansson, PhD candidate  
Centre for medical ethics

# 1. Why did we perform an interview study with patients with severe mental illness about family involvement?

- To gain knowledge that can inform clinical practice and implementation of family involvement in severe mental illness (narrowing a theory-practice gap).
- Patient experiences with family involvement is lacking in the scientific literature (narrowing a scientific gap).
- Participatory action/responsive evaluation design.  
«All voices count».



# Research question

How do patients with psychotic disorders experience systematic family involvement, and what significance does this family involvement have?

## 2. Methods

- Semi-structured, individual interviews with patients that were exposed to the IFIP-intervention: BFIS and FPE.
- Interviews by Zoom/phone.
- Purposive sampling.
- Inclusion criteria: an established or tentative psychotic disorder, 18 years of age or older, capacity to consent, and exposure to BFIS and/or FPE in the intervention period.
- Exclusion criteria: not being competent to consent; not having any relatives, being a forensic patient, or having an increased risk of violence.
- Recruitment process in collaboration with staff at the interventions units.
- Audio recordings transcribed verbatim.
- Qualitative content analysis.

# The IFIP intervention

## Clinical interventions:

- I. Basic Family Involvement and Support (BFIS)
  - At least three conversations about family involvement
  - Written information
  - Psychoeducative seminars for relatives
  - Crisis/coping plan
  
- II. Family psychoeducation (FPE) in single-family groups
  - Engagement and alliance sessions
  - Warning signals, crisis/coping plan, genogram, goals of treatment
  - Psychoeducation
  - Communication skills and exercises
  - Problem-solving sessions

## Participant characteristics (n=13)

<b>Age</b>	The age ranged from 26-60 years, with some more participants below the age of 40.
<b>Years since time of diagnosis</b>	7 of the participants were diagnosed 0-5 years ago, 3 participants 10-20 years ago, and 3 participants over 20 years ago.
<b>Family involvement</b>	9 out of 13 had participated in alliance and joint sessions at the time of the interviews.
<b>Next of kin participating in family involvement</b>	Parents, parents and their partners, husband, wife, sister, brother, aunt, children, professionals in mental health supported accommodation services.

# Interview guide

## **1. Family and family involvement**

- Who is important to you in your everyday life? Has your therapist or anyone else at the CMCH been in contact with them?
- How have your closest relative(s) been involved in your treatment here at the CMCH?

# Interview guide cont.

## 2. Experiences with- and significance of family involvement

- **What has the family involvement meant to you?**
  - o How was it for you to participate in...?
    - Was there anything you thought was good (about participating in...)?
    - Was there anything you found difficult (with participating in...)?
    - Do the therapists and your family listen to you? Are they interested in your opinions?
  - o If the participant has participated in FPE: We know that some users experience that FPE has contributed to the process of recovery. What do you think about that? If positive: How has it been useful?
  - o Was the form of collaboration important to your experience?
  - o If negative: In what way do you feel that participation in FPE has been negative?
- **What do you think the family involvement has meant to your family?**
  - o Do you perceive that your family/network has received support and help to understand what you are struggling with?
  - o Have they been more helpful to you afterwards?
- **For family involvement being helpful to you:**
  - o What do you want from your therapist?
  - o What do you want from your closest relatives?
- **Is there anything else you would like to share?**



## 3. Findings

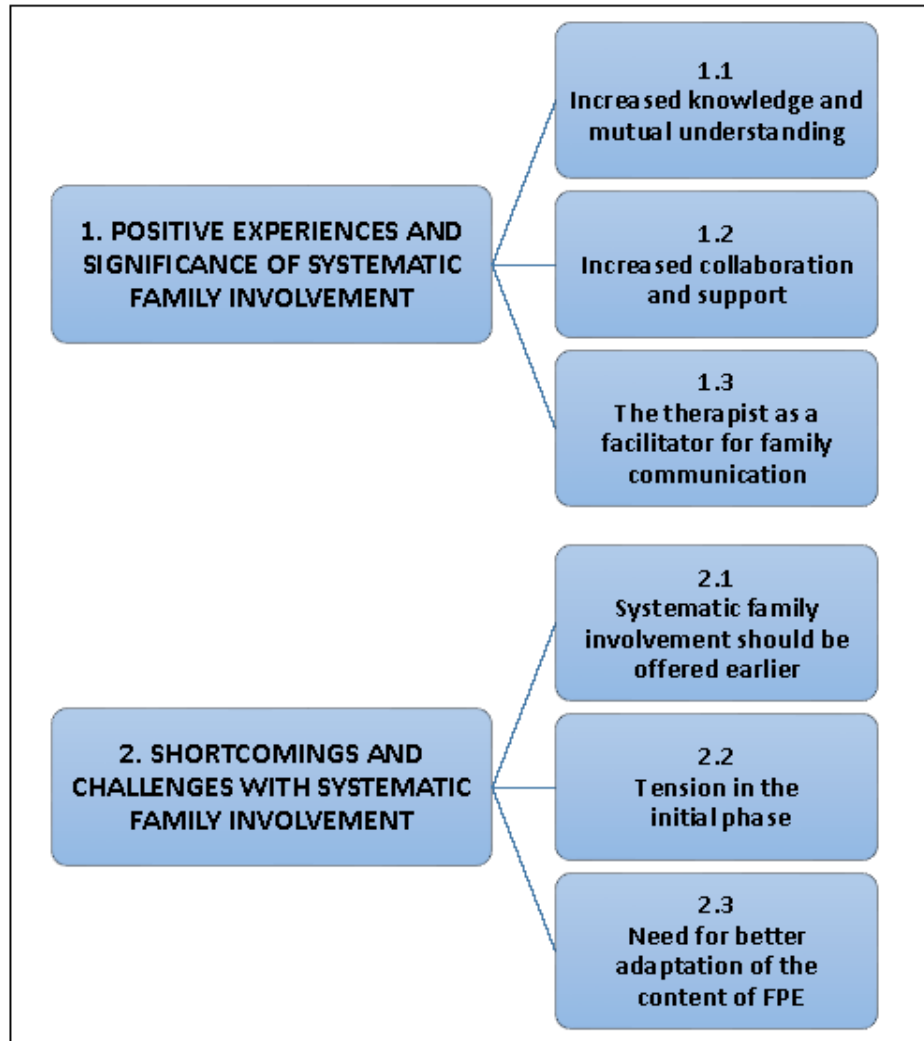
### **Two main themes, six sub-themes**

1. Positive experiences and significance of systematic family involvement.
2. Shortcomings and challenges related to systematic family involvement.

### **Additional, yet important background information**

- Life with mental illness from before attending the study.
- The burden the disease had caused their relatives.

Figure 1. Thematic map of patient experiences and significance of family involvement



## 1.1 Increased knowledge and mutual understanding

“I think my partner found it very useful. If I experience stress ... how to avoid it, other causes of psychosis, prevent it a little.”

# Increased knowledge and mutual understanding

“The most important positive change that happened was that my father finally understood that there was something wrong ... that I haven't been well for a long time ... he got it like a punch in the face, as he said himself. He has changed for the better after that, I think.” (The researcher asks what had changed): “He doesn't push me so much anymore ... has started to show interest ... he is more into the conversation when I tell him about things I like, and he listens better.”

# Increased knowledge and mutual understanding

“My aunt has in a way learned more about what I really need and how things are for me ... she didn't have much insight into things before ... she can perhaps be a bit like ‘can't you just do this and that, or just stop taking your medication, or stop putting on weight?’” - maybe this has changed ... she has more patience with me, she understands me better. I also feel that, in a way, I have gained more trust in her.”

# Increased knowledge and mutual understanding

“My mother said that “based on everything that has happened, you have experienced something and I have experienced something, but we have not experienced it together”. And when acknowledging this, she has actually got the answers she needs. Because then she can see that I see it differently ... and I can understand that she sees it differently. This is something of the most important I have gained from family psychoeducation”

## 1.2 Increased collaboration and support

“I feel more safe in the social contexts because those closest to me are more involved in how I feel, and know more about what I am going through.”

## Increased collaboration and support

“I had imagined it would be very uncomfortable ... very personal. Rather, we addressed a problem that is bothering me at the moment, and we discussed what everyone could do to make it better. It was a very pleasant way of doing it, focusing on a specific problem rather than what I had envisioned”.



## Increased collaboration and support

“The symptoms have been stopped from...becoming psychosis. By using the things we have set up for the family collaboration ... warning signals indicating things are getting difficult and ...what I have to do to not being ill.”

## Increased collaboration and support

“The first time, my mother was so nervous. But then she was so satisfied ... it helped her to talk a little ... There is probably a lot she is ashamed of. You know, it's no medallion to have a drug addict son.”

## Increased collaboration and support

“My husband and mother have the therapist's mobile number. Lately they have been worried about my food intake. Then I think it is better that they call therapist rather than them taking out their frustration on me.”

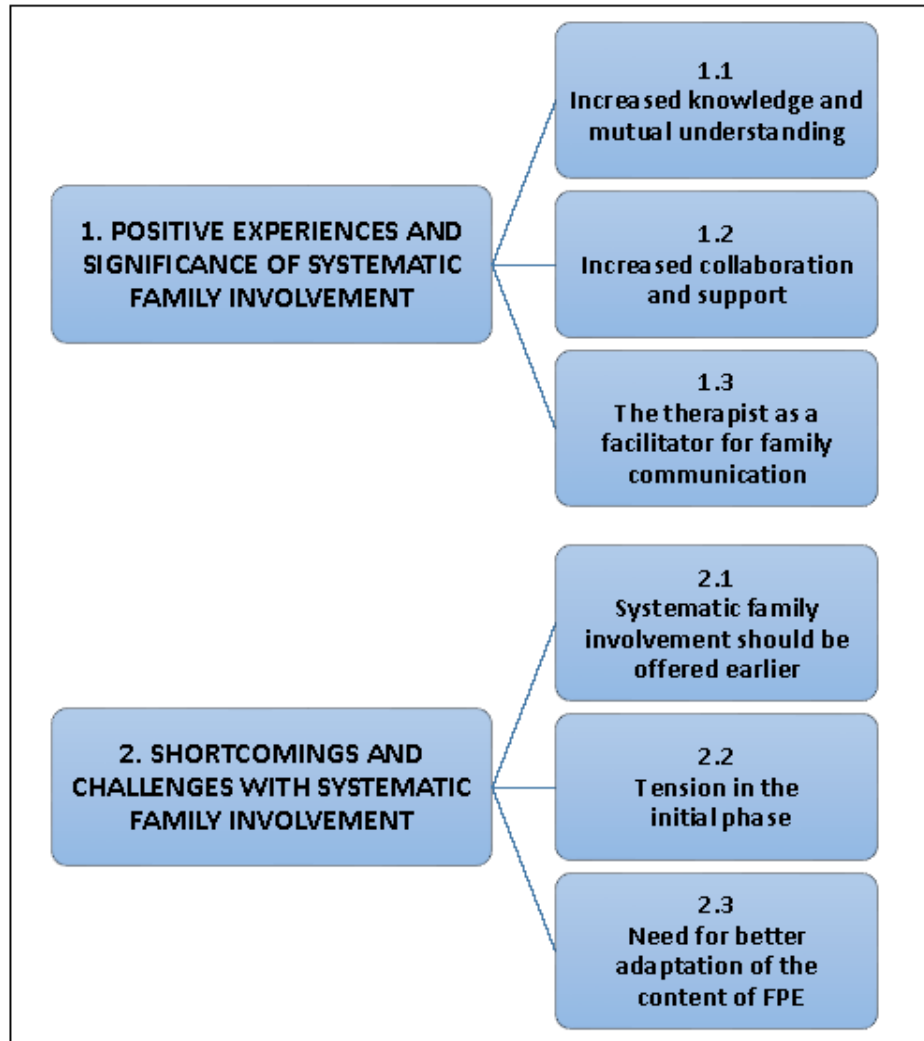
## 1.3 The therapist as a facilitator of family communication

“I find it difficult to talk to my parents about how I feel. I haven't been able to do it myself, so I think it was very nice for them to hear such a calm version of how things are, and to be able to ask the questions they had.”

## The therapist as a facilitator of family communication

“I get a little scared when I think about me, the therapist and my mum shall sit and talk together, because I haven't done that for a long time ... I'm not lying that I've been high, but I don't want to worry her ... but with the therapist there ... He is quite stable, so I think I will be able to convey it well with his help.”

Figure 1. Thematic map of patient experiences and significance of family involvement



## 2.1 Systematic family involvement should be offered earlier

“My family should have been involved when I first got sick. When I started at the psychologist's, when it all started, the child protection services and everything...”

## 2.2 Tension in the initial phase

“It's not that I don't want to, but I've been afraid. Until now.”

“I imagined that it was going to be me who had to speak, or that it was going to be uncomfortable. Such meetings [FPE-sessions] are often set up a long time in advance, so there were many weeks of uncertainty. I lived in my parents` house then too - yes, I think it was a bit difficult. Because at the same time they met with my therapist [alliance sessions]. I think it was uncomfortable that they met each other while I was just waiting, in a way.”



## 2.2 Tension in the initial phase

“One thing I really liked was that I got to decide what the therapist was going to say to my parents”.

“Just make it very clear that it is not as unpleasant as one might imagine, then. It is rather just that we look at the problems together ...”

## 2.3 Need for better adaption of the content of FPE

“There has been a lot, a lot of focus on me and ‘my things’.  
Perhaps [there should have been] even more focus on my partner”.

## 4. Discussion

The participants described overall positive experiences with participating in family involvement and that family involvement contributed to a positive change within the family system.

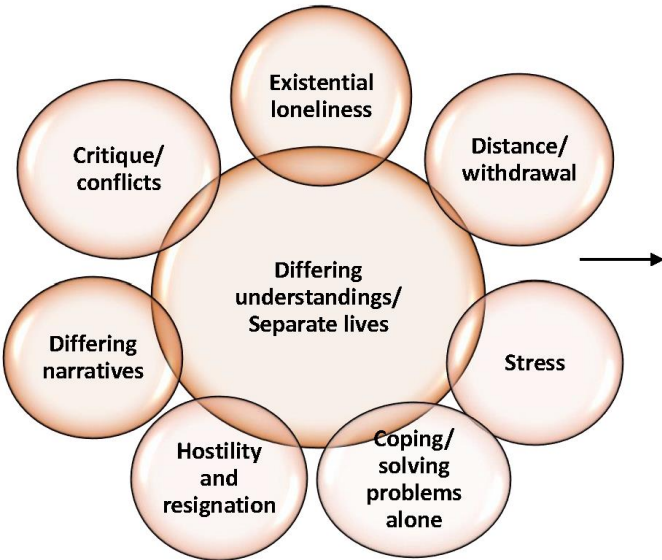
What processes seemed to contribute to this change?

# How family involvement seemed to improve the family dynamics:

## Potential mechanisms of impact

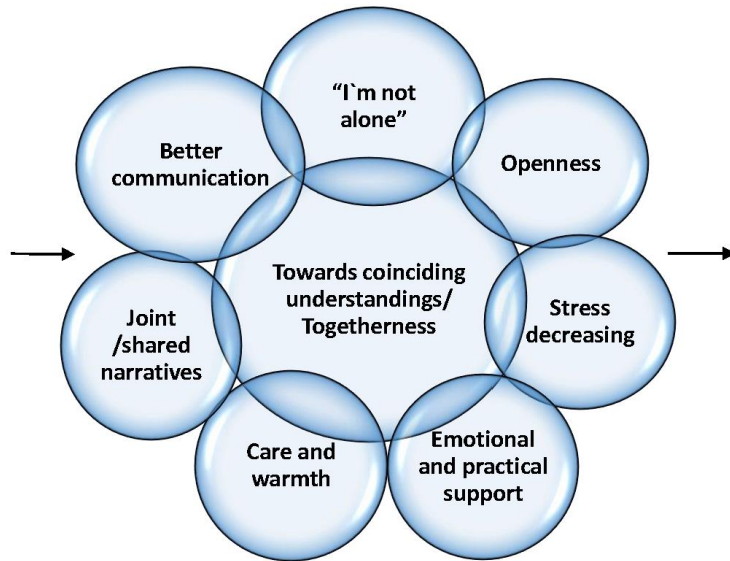
- Access to knowledge and guidance to understand psychosis.
- Experiences of being acknowledged and understood.
- Taking part in the narratives of their significant others.

**A) BEFORE SYSTEMATIC FAMILY INVOLVEMENT**



Systematic family involvement (BFIS+FPE)

**B) AFTER SYSTEMATIC FAMILY INVOLVEMENT**



- C) Possible patient outcomes e.g.:**
- Reduced rates of relapse
  - Reduced rehospitalisations
  - Improved medication adherence
  - Improved social function

# Family involvement - timing is crucial

## Family involvement should...

- ... start early
- ... focus on the initial phase
- ... be tailored

# Strengths and limitations

- Findings cannot demonstrate causality.
- We do not know for certain what kind of family involvement the participants have been exposed to - or how much.
- Risk of observer bias, normative standing of the researchers.
- Tailored inclusion; pros and cons (sample bias?)
  
- Nested in a comprehensive implementation study, real-life clinical setting.
- Rich first-hand data from a patient group whose voices are seldom heard.
- Great variation in sample.
- Other IFIP sub-studies indicate coherence in findings.

## 5. Conclusions

- Participants reported **overall positive experiences** with family involvement during psychotic illness with positive impacts for themselves, their relatives, and the family environment.
- Engaging with their relatives, with help from professionals, led to a series of **meaningful changes related to family interaction**.
- Common therapeutic factors, education about the illness, and problem solving facilitated **increased knowledge of psychosis** and **mutual understandings of each other's situation and experiences**.
- These new insights further stimulated a **more collaborative and supportive family environment** that promoted better overall coping with the psychotic disorder.
- **The therapist was critical in promoting these processes** as a facilitator of patient-relative communication, a creator of a safe, contained space, and continuous support for the relatives.
- **“Helping the helpers”** was described as imperative to prevent relapse and promote health and wellbeing among both patients and relatives.
- It is important to **start with family involvement early** after the onset of a psychotic disorder, to pay special attention to the **initial phase**, use a **step-wise approach**, and ensure that FPE content are **adapted to each patient and his/her family's needs**.
- Basic levels of family involvement and FPE should be implemented as a **standard approach** in the treatment of persons with psychotic disorders.
- Findings from this study can **guide future practice and efforts to implement family involvement** in CMHCs.



